

**NON-GOVERNMENTAL ORGANIZATIONS AND HIV/AIDS IN KOLKATA,
INDIA: A DISCURSIVE ANALYSIS OF POLICY AND PROGRAMMING**

By

Elizabeth Grace Williams

A thesis resubmitted to the University of Plymouth

in part fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Law and Social Science

November 2009

Elizabeth Grace Williams

Non-Governmental Organizations (NGOs) and HIV/AIDS in Kolkata, India: A discursive analysis of policy and programming.

This thesis presents the findings from a study that explores the language and discourses of HIV/AIDS in India circulating at different levels of the policy process during the early years of the pandemic, with a particular focus upon the work of NGOs in Kolkata, West Bengal. The study was exploratory and used Walt and Gilson's (1994) analytic framework of content, context, actors and process to guide data collection.

Eleven NGOs were identified for case studies using a snowballing technique. The research design used multiple methods of data collection including semi-structured interviews, informal interviews, participant observation, the keeping of a research diary, and the collection of documentary sources, including policy documents, grey literature and Behaviour Change Communication (BCC) material. The texts were analysed using discourse analysis following Carabine (2002).

The study found that global and national level policies assigned a significant role to NGOs in three areas: prevention and control, care and support of people living with HIV/AIDS and the promotion of human rights. However, at the state level there was marked ambivalence about working with NGOs and considerable disagreement about the extent of the pandemic. HIV/AIDS was constructed as un-Bengali and a problem for marginalized and poor groups. The targeted interventions approach, adopted for use at the time, seemed to offer a mismatch between problem construction and responses. However several of the NGOs in the study were offering a package of holistic services in addition to the targeted interventions. NGOs faced

the problem of how to share these experiences and understandings with the wider policy community as there was limited opportunity to do this. Further, the involvement of NGOs in care and support was limited and they faced difficulties in promoting a human rights based approach to their work, in part because of a lack of support from the State AIDS Prevention and Control Society (SAS).

The findings suggest that, within the context of West Bengal, policies need to be realistic in the role assigned to NGOs in HIV/AIDS programming, clearly identify a role for the state in the promotion of human rights, and develop strategies to enable NGOs to contribute their knowledge and expertise to the policy process.

List of contents

	Page
Chapter 1 Non-Governmental Organizations and global public health	
1.1 Introduction	5
1.1.2 Overview of chapter	8
1.2 Defining the term NGO	9
1.3 The policy context of Non-Governmental Organization.	
1.3.1 Historical antecedents	12
1.3.2 The New Policy Agenda	14
1.3.3 Globalization	15
1.3.4 Global Public Health	16
1.3.5 The World Bank, health policy and NGOs	18
1.3.6 How do NGOs feature in this?	20
1.4 NGO Performance: the substance behind the rhetoric	
1.4.1 What do health sector NGOs actually do?	21
1.4.2 Addressing the political dimension	21
1.4.3 Legitimacy and accountability	23
1.4.4 NGO performance: strengths and weaknesses.	25
1.4.4.1. Cost-effectiveness	25
1.4.4.2. Reaching the poorest of the poor	28
1.4.4.3. Cooperation and inter-organizational working	30
1.4.4.4. Technical and managerial issues; capacity building and sustainability	31
1.5 Conclusion	32

Chapter 2 HIV/AIDS programming in resource-poor settings

2.1	Introduction	35
2.2	HIV: A global pandemic and a global response	
2.2.1	HIV and its identification as a 'pandemic'	37
2.2.2	The emergence of a global response to HIV/AIDS	40
2.2.3	UNAIDS: A different form of international response	42
2.2.4	Alternative Voices	45
2.3	Competing discourses in HIV/AIDS policy	
2.3.1	Introduction to biomedical discourses	47
2.3.2	Biomedical understandings of HIV	48
2.4	Constructing risk and vulnerability	
2.4.1	Risk groups	49
2.4.2	High Risk Situations	52
2.5	HIV/AIDS programming within resource poor settings	
2.5.1	Introduction	54
2.5.2	Prevention and control	
2.5.2.1	Targeted Interventions- defining the terms	56
2.5.2.2	Overview of different intervention strategies	57
2.5.2.3	Strengths and limitations of approaches	60
2.6	Normalizing the pandemic	63
2.7	Care and Support	
2.7.1	Introduction	64
2.7.2	Care and support. What are the issues?	66
2.8	Concluding comments	68

Chapter 3 Methodology and Methods

3.1	Introduction	70
3.2	The analytic Framework	
3.2.1	Introduction	70
3.2.2	The work of Walt & Gilson	71
3.2.3	Introduction to epistemology	73
3.2.4	Central themes in post-structuralism	74
3.2.5	Reflexivity: Introducing the concept	76
3.2.5.1	Implications for the researcher	78
3.2.5.2	The professional/researcher divide	79
3.2.5.3	Constructing a narrative of self	82
3.2.5.4	Strategies for reflexive practice	88
3.3	Research design and methodology	
3.3.1	The research questions	90
3.3.2	Research design	92
3.3.3	Ethics, informed consent and confidentiality	93
3.3.4	Identifying sources and data collection methods	94
3.3.5	Data Analysis: Foucault and Genealogy	97
3.3.5.1	Select your topic	98
3.3.5.2	Know your data: read, re-read and read again	101
3.3.5.3	Identify themes and categories and objects of the discourse	101
3.3.5.4	Absences and silences	104
3.3.5.5	interrelationships between discourses	104
3.3.5.6	Context	105
3.4	Data Collection and field work	
3.4.1	Time frame of study	106
3.4.2	Identifying gate keepers and key respondents	106
3.4.3	The NGOs	110
3.4.4	researcher/nurse divide	114
3.4.5	Ethics and reflexivity	116
3.5	Concluding comments	118

Chapter 4 Constructing Indian AIDS

4.1	Introduction	121
4.2	The ‘problem’ of HIV/AIDS in NACO policies	124
4.3	Identifying Risk Groups	
4.3.1	Early epidemiological studies and prevailing social norms	128
4.3.2	A foreign threat and an ‘un-Indian’ epidemic	131
4.3.3	A globalization of categories and orientalist discourses	132
4.3.4	The controversy over figures	134
4.3.5	The most infected mantle and ‘African’ AIDS	135
4.3.6	Counter discourses and post-colonial readings	136
4.4	Globalization and constructing the nation-state	
4.4.1	Introduction	139
4.4.2	Hiv/AIDS as a threat to security – imagining the nation	141
4.4.3	Making the connections with HIV/AIDS policy and programming	144
4.5	Indian AIDS: Discourses of deviancy and poverty	
4.5.1	Introduction	147
4.5.2	HIV/AIDS the poverty dimension	148
4.5.3	Men who have sex with men	150
4.6	Discussion and concluding comments	153

Chapter 5 The development of HIV/AIDS related policies in West Bengal and the role of NGOs

5.1	Introduction	157
5.2	Context	
5.2.1	Geography, history and economics	159
5.2.2	Political considerations	161
5.3	Understanding the epidemic in West Bengal	
5.3.1	Introduction	163
5.3.2	Sero surveillance	164

5.3.3	Weaknesses in sero surveillance	165
5.3.4	Sentinel surveillance and AIDS case reporting	167
5.3.5	Discussion	168
5.4	The evolution of HIV/AIDS policy in West Bengal	
5.4.1	Introduction	169
5.4.2	Governance and NGO/State relationships	171
5.4.3	NGOs and the National AIDS Control Programme 2	174
5.4.4	West Bengal sexual health project	
5.4.4.1	Introduction	175
5.4.4.2	Aims of the project	176
5.4.4.3	Overview of the approach	177
5.5	Developing themes	
5.5.1	Introduction	179
5.5.2	The handover	180
5.5.3	Contested meanings	183
5.5.4	NGO- a fragmented site	185
5.6	Concluding comments	187

Chapter 6 Competing Discourses in HIV Prevention and Control: NGOs and HIV/AIDS Programming in West Bengal.

6.1	Introduction	190
6.2	Discourse of Risk and Vulnerability	
6.2.1	Introduction	191
6.2.2	Techniques for Identifying Risk Groups	191
6.2.3	An Emerging Discourse	193
6.2.4	Effects of Migration	195
6.2.5	Occupational Basis to Groups	196
6.2.6	Power Relations	197
6.2.7	Psychological factors	198

	6.2.8	Challenging the Idea of Risk Groups	199
	6.2.9	Gender and Sexuality	200
6.3		Addressing the Human Rights Dimension	
	6.3.1	Introduction: Risk Groups, Stigma and 'Othering' the epidemic	202
	6.3.2	A culture of 'no-blame' within NGOs	203
	6.3.3	Negative Consequences	205
	6.3.4	Enabling Environments and Human Rights	206
	6.3.5	Creating an enabling environment	207
6.4		Competing discourses and contested meanings	
	6.4.1	Introduction	209
	6.4.2	Background to the DMSC	210
	6.4.3	Strategies to raise awareness of their approach	212
	6.4.4	Alternative approaches and opposing viewpoints	214
6.5		Responding to Felt Need	
	6.5.1	Introduction	215
	6.5.2	NGO interventions	216
	6.5.3	Targeting men who have sex with men	220
6.6		Concluding Comments	223

Chapter 7 NGOs and the provision of Care and Support for People living with HIV/AIDS

7.1		Introduction	226
	7.1.2	Inter-subjectivity and the researcher/nurse divide	229
7.2		The framing of care and support	
	7.2.1	Background to care and support in India	231
	7.2.2	Care and Support- a lack of options	233
	7.2.3	A Discourse of Despair	232
	7.2.4.1	The World Bank approach	235

	7.2.4.2	Indian Responses	236
7.3		Identifying need in project users	239
7.4		What does care and support entail?	241
7.5		Care and support the NGO approach	242
	7.5.1	HIV testing and pre and post test counselling	244
	7.5.2	Other forms of psychological support	246
	7.5.3	Accessing formal health care	248
	7.5.4	Community and home based care and support	249
7.6		Enabling and Constraining Factors	
	7.6.1	Introduction	251
	7.6.2	Professionalism	252
	7.6.3	Funding	253
	7.6.4	Inter organizational collaboration	255
7.7		Discussion	256

Chapter 8 Discussion and Recommendations

8.1		Introduction-	259
8.2		Contribution to new knowledge	259
8.3		Summary of main research findings	
	8.3.1	Discourses of risk and vulnerability	263
	8.3.2	Implications for prevention and control and care and support	264
	8.3.3	Relationships within the policy process	266
8.4		Strengths and Limitations of the study methodology	267
8.5		Implications for policy	272
	8.5.1	Introduction	272
	8.5.2	A better understanding of the HIV/AIDS pandemic in West Bengal	272

	8.5.3	Enhancing NGO performance and widening their sphere of influence	275
	8.5.4	The limitations of NGOs and the necessity of re-thinking some aspects of their role	278
8.6		Concluding comments	279
		References	280

Acknowledgements

I would like to acknowledge the University of Plymouth for providing funding for my year of research training. I would also like to acknowledge the Economic and Social Research Council for providing a scholarship for this research.

At the University of Plymouth my director of studies, Professor Sheena Asthana, has offered unwavering academic support, advice and encouragement over the course of this study. I will always be grateful to Sheena for greeting the birth of my daughter with joy, for supporting me in the difficult decision to take time away from the study and for welcoming me back without equivocation. In addition Dr John Dixon offered me help and advice in the first year of this research and Cher Cressy, the graduate administrator in the faculty office, has been consistently helpful and kind over the course of this study.

Although he was not involved with this particular piece of work I wish to acknowledge Denis Judd, Professor of British and Commonwealth History at London Metropolitan University. Denis was an inspiring tutor and I am indebted to him for his support and encouragement during my time as an undergraduate.

There are many people in India that I would like to thank. First and foremost I am grateful to the people who helped me with this study, both as gate-keepers and as research participants. The need for confidentiality prevents me from mentioning many of these people in person however two people to whom I wish to pay a special mention are Shumon Sengupta of the former West Bengal Sexual Health Project who showed me great kindness and gave generously of his time and Dr Arup Chakrobarty for his friendship.

As a foreign student, researching a sensitive topic, I asked a lot more of people than I had any right to expect. I was greeted with a warmth and generosity of spirit that has remained with me during the lengthy period that it has taken me to complete this thesis.

I also wish to thank fellow PhD student Dr Indranil Chakrobarty for sharing his insights and research contacts with me at an early stage of the field research and Mondira Bhaduri for her friendship and Bengali lessons.

On a personal level I wish to thank Dr Paul Boyce for sharing the research experience in Kolkata, for the friendship that has grown from that shared experience and for the immense kindness and support that he has shown to myself and Greta over the past difficult year. I also wish to acknowledge Helene, Julie and Mokka, my friends from Calcutta Rescue days.

I wish to thank my partner David for his enduring faith in me. David has shared the uncertainty, the frustrations and financial hardships of this seemingly endless thesis with me and has done so with grace, constancy and love. It is impossible to give voice to the many ways in which David has supported me over the past year. I hope one day (soon) that I will earn so that you will more time to paint David.

My mother-in-law Dr Sylvia Hardy has also been unfailing in her support and encouragement. My sister Anna has been kind, encouraging and generous to her perpetual student of a sibling.

Finally I wish to acknowledge the love, and encouragement of my parents Desmond and Bernice Williams who never wavered in their support of me. It is with more sadness than I can say that my mum died before I was able to complete this thesis. You have been with me all of this past long year Mum, always in my heart.

Author's declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award.

This study was financed with the aid of studentships from the University of Plymouth and the Economic and Social Research Council.

Conference presentations:

Paper accepted for poster presentation at the XIV International AIDS Conference, Barcelona 2002:

The role of non-governmental organizations in the provision of community and home based care and support for people living with HIV/AIDS: putting theory into practice in West Bengal.

Paper presented at the British Social Policy Association Conference, Belfast, 2001:

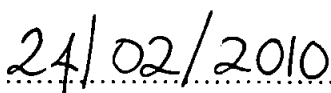
A human rights based approach to the provision of low cost care for people living with HIV infection and AIDS: The implications for policy in India.

Paper presented at the Emerging New Research in the Geographies of Health and Impairment Conference, University of Portsmouth, 1999:

Reconciling the global with the local in HIV/AIDS policy: A critical examination of HIV/AIDS policy in India.

Word count of main body of thesis: 81100

Signed.....

Date.....

Introduction

When this study was first conceived of (in the autumn of 1997), alarm bells were beginning to ring at the international level about the potential threat to India of HIV/AIDS. The World Health Organization was estimating that between three and five million people were already infected with HIV in India (Lichfield 1997). It was also suggested that by 2000 India might have the highest rates of HIV infection of any country in the world (Laino 1995). Emerging patterns of infection in discrete populations supported the view that HIV presented a serious threat to public health (Gilada 1991).

However, it was difficult to draw any firm conclusions about the size and extent of the pandemic at that time because testing was largely confined to members of highly stigmatized groups such as commercial sex workers and injecting drug users. This approach was a reflection of the manner in which AIDS was already being constructed as a disease of deviancy and as essentially un-Indian within Indian policy circles. As Asthana notes, the response of the Indian government could best be described as one of apathy and denial (Asthana 1996). Further there was a failure to engage with the potential threat of HIV to the population as a whole.

At the national level the Indian government established a National AIDS Control Organization (NACO) in 1992 with funding from the World Bank (Priyya 1994b). NACO adopted the planning recommendations laid down initially by the World Health Organization's Global Programme on AIDS (GPA) and subsequently by UNAIDS which focuses upon the need for strategic planning (UNAIDS 1998). This entailed surveillance of HIV rates in all states, technical support and care for people living with HIV and AIDS (NACO 1999). However, throughout the 1990s risk and

vulnerability to HIV infection continued to be associated with marginalized or deviant identities (Karnik 2001) and consequently national level policies responded by identifying a significant role for Non-Governmental Organisations (NGOs) (NACO 1999, NACO 2000).

Against this background, the purpose of this research is to explore the language and discourses of HIV/AIDS in India circulating at different levels of the policy process, between the mid 1980s and 2001 (when the final stages of the field research for this study was carried out) with a particular focus upon the work of NGOs in Kolkata, West Bengal. The thesis makes a substantive, and a theoretical, contribution to new knowledge in four distinct but overlapping areas. First, the study contributes to knowledge about the transfer and translation of policies for HIV/AIDS prevention and control, from the global level to the national level in India, and thence to the state level in West Bengal and finally, the NGO level in Kolkata. Second, this study contributes to an emerging body of literature concerned with new ways of theorizing the term Non-Governmental Organization, in order to better understand the roles that NGOs play in policy design and implementation. Third, the study contributes to knowledge about the different discourses of HIV/AIDS in circulation in India, and West Bengal, and the ways in which these inform and engage with approaches to prevention and control and care and support. Fourth, the study offers a substantive contribution to knowledge regarding the incorporation of reflexivity into the research process and the researcher/nurse divide (see pages 259-262 for a detailed discussion of these).

The chapter structure in this thesis is as follows. Chapter one explores the literature relating to NGOs and their increasing role in the delivery of health care and health related activities within the context of resource poor settings and against an

emerging backdrop of 'global public health'. Chapter two is concerned with a specific public health problem, HIV/AIDS, and the global response to this threat. It also maps out the manner in which NGOs have been incorporated into this response. Chapter three provides a discussion of the theoretical approach taken to the research and how this was implicated in the overall research design. It also provides an account of the actual research process including fieldwork and data collection, data analysis and writing.

Chapters four, five, six and seven present the research findings. Chapter four provides an exploration of the discourses of HIV/AIDS in circulation in India at the time of the study, and the implications of these discourses for the development of policy and programming, including a role for NGOs. Chapter five, drawing upon the work of Walt and Gilson (1994), considers the context, content, actors and process involved in the development of these policies, within the context of West Bengal. In doing so it considers the manner in which the multiple relationships between different actors and institutions influenced the translation of policies at the state level.

Chapter six takes as its focus, the work of local level NGOs in HIV prevention and control and the understandings of the risk and vulnerability upon which this work was based. Chapter seven is concerned with the manner in which local level NGOs in West Bengal engaged with the need to provide care and support for those infected/affected by HIV/AIDS and factors that restricted this response. Finally chapter eight provides a conclusion to the study. As such it offers an opportunity to reflect upon the study as a whole, discussing the ways in which the study makes a contribution to new knowledge and summarizing the research findings. It then considers the strengths and limitations of the study methodology, including the issue

of reflexivity. The chapter concludes by considering the implications of the study for further research and policy development.

Chapter 1

Non-governmental organizations and global public health

1.1 Introduction

NGOs have been actively involved in the response to HIV/AIDS since the early days of the pandemic. In the industrialized world they took on an activist role improving access to experimental drugs and health care, acting as advocates for persons living with HIV/AIDS (PLWHA), developing and disseminating targeted educational material and spearheading the involvement of peer educators in outreach programmes (Mercer et al 1991). Crucially they emerged from within the communities most affected by AIDS (Asthana & Oosvogels 1996). As such they gave a voice to the marginal and discriminated against at a time when the governments of the countries most affected (USA, UK, Australia and Western Europe) were slow to respond to the unfolding pandemic and, when the debate both politically and within the popular media, was inimically tied up with 'victim blaming' (Garfield 1994). Within this climate, NGOs put human rights at the forefront of the policy agenda. Today the maintenance of human rights is an integral part of all HIV/AIDS programming (United Nations 1996).

The importance of the contribution made by NGOs to the global challenge of HIV/AIDS prevention and control was formally recognised by the UN as early as 1989 with a resolution from the World Health Assembly. This noted that their:

...commitment and versatility, and their knowledge and experience....can make a special impact upon individuals and society regarding AIDS and the needs of HIV-infected people and those with AIDS. (World Health Organization/Global programme on AIDS 1989 cited in Mercer et al 1991: 266).

By the time that HIV infection began to emerge in the developing world, the importance of NGO involvement was firmly established by leading global players in HIV/AIDS prevention and control. For example the WHO's Global Programme on AIDS and the World Bank, had formerly assigned a pivotal role to NGOs in HIV/AIDS prevention and control (World Bank 1998, Mann & Kay 1991).

This research project is concerned with the evolving role that was assigned to NGOs in the design and implementation of HIV/AIDS policies in Kolkata, West Bengal during the early years of the HIV/AIDS pandemic in India. As this thesis will explore, this role was fundamental to the overall aim, as expressed in policy documents, of controlling the spread of HIV (NACO 1999, NACO 2000). Latterly this role also extended to the provision of care and support for those infected/affected by HIV. Both of these functions were premised upon the belief that NGOs would be able to act as advocates in promoting and protecting the human rights of vulnerable groups and individuals believed to be at high risk of contracting the infection.

Given this focus, this chapter will explore the literature relating to NGOs and their increasing role in the delivery of health care and health related activities within the context of resource poor settings and against an emerging backdrop of 'global public health' (Edwards & Hulme 1996, Shirin 1995). There is nothing new about the involvement of NGOs in the 'business' of health. However the current status of NGOs has arisen within a rapidly evolving policy environment. First, the political and economic doctrines of Market liberalization and Good Governance that emerged following the collapse of Communism in the late 1980s heavily promoted NGOs in place of the state (Edwards & Hulme 1996).

Second, the process of globalization has impacted upon both the factors contributing to health and illness within populations and to the development of health policies aimed at addressing them (Lee et al 2002, Parker 2006). Against this background, NGOs are being incorporated into the health arena in increasingly complex ways. The fundamental questions of *who* is designing health policy, *where* this takes place and *how* health is conceptualised offers a means of reading the meteoric rise of the NGO as one that is essentially political. As such this 'associational revolution' (Salamon 1994) owes more to political ideology than to the engagement of policy makers and practitioners with a body of evidence that unequivocally shows the superiority of NGOs over and above the public sector (Fowler 1996).

Perhaps unsurprisingly, until recently, the published literature has largely neglected the political nature of the emergence of NGOs onto centre stage despite a burgeoning literature around globalization (Clarke 1998). This is unfortunate for a number of reasons. First, the turn towards NGOs for service delivery raises important questions about the legitimacy and accountability of these NGOs. Second, it calls into question the role and responsibility of the State in providing for its citizens. Third, the increasing preference of international donors and bilateral governments to channel their aid and development budgets through 'Southern' NGOs rather than through government departments has an implicit political dimension to it with respect to sovereignty. Fourth, at the micro level, despite the Governance agenda, the essentially political characteristic of NGOs in their role as activists and agents for change is being eroded by the imposition of external agendas and the competition for contracts to provide services designed elsewhere. As such NGOs stand accused of co-option (Shirin 1995, Edward & Hulme 1998, Lorgen 1998).

1.1.2 Overview of chapter

This chapter will be structured as follows. It will begin with an explanation of how the term 'NGO' is being used in this study. This will be followed by a discussion of 'The New Policy Agenda' (NPA). This has provided the political and economic drive for the rise in the number, scope and scale of NGOs. The aims and intentions of the NPA have been well served by the increasingly globalised nature of relationships between states, and between citizens, institutions and organizations within states and across state borders. Therefore the process of globalization will be discussed next with a particular focus upon the emergence of 'global public health' and the meteoric rise of the World Bank. What are the implications of this trend for NGOs working in health?

Having explored these concepts the second half of the chapter will discuss a number of inter-related issues concerning NGO legitimacy and accountability and their actual performance. First, why has so little attention been paid to the inherently political nature of NGOs? Second what issues underlie their claims to legitimacy and accountability? Third what are their reputed strengths and weakness? It will be argued that there is very little evidence to support some of the claims made for NGOs and that their rise in prominence is essentially ideologically driven. What are the implications of this for health policy and the management of infectious diseases within resource poor settings?

1.2 Defining the term Non-Governmental Organization

First, it is important to clarify how the term NGO is used. Green and Mathias offer the following definition for NGO:

...formal organizations which have corporate objectives concerned with humanitarian aims concerning groups outside of the organization, which are non-profit making and which are outside the direct control of government. (Green & Matthias 1997: 9).

This definition is useful and identifies a number of key characteristics of NGOs.

First, they operate as corporations, suggesting that they have the organizational structures and processes one would associate with the private sector. For example ultimate sanction in decision-making lies with a board of trustees. Second their aims are humanitarian. Third, NGOs are not directly controlled by the government in the manner that public sector organizations would be although the state does have a regulatory function. Fourth, and very importantly, the people working for the NGO are distinct from the groups that it aims to work with. This draws a clear distinction between NGOs and Grass Roots Organizations (GROs) and Community Based Organizations (CBOs). Although the term NGO is sometimes used to incorporate CBOs and GROs this causes confusion. The latter are usually membership organizations and are therefore accountable to the membership. NGOs on the other hand are service organizations and have clients or beneficiaries. These clients or beneficiaries cannot hold an NGO to account in the same way that they could a membership organization (Edwards & Hulme 1998). One area of contention within this definition is the assertion that NGOs are non-profit. In reality some NGOs do make profits, for example by charging user fees (Dave 1991, Gilson et al 1994).

Clarke expands on this definition to include the types of organizations that can be classed as NGOs. He also gives a good indication of the range of work carried out:

NGOs are private, non-profit, professional organizations, with a distinctive legal character, concerned with public welfare goals. In the developing world, NGOs include philanthropic foundations, church development agencies, academic think-tanks and other organizations focusing on issues such as human rights, gender, health, agricultural development, social welfare, the environment and indigenous peoples...They are distinguished from People's Organizations because these are membership based.... (Clarke 1998 :36-37).

Identifying that NGOs have a distinct legal character is important because all governments will have legislation dealing with how they should operate. Again Clarke says that they are non-profit making but he does distinguish between NGOs and People's Organizations on the basis of membership.

As these definitions suggest, the term NGO is used to describe a wide range of different organizations and there is a danger that the degree of homogeneity implied by its use blurs the distinctions between the scope, size and orientation of different organizations (Sen 1999, Mageli 2005). At times, authors use a variety of acronyms to distinguish between the size or location of NGOs - for example INGO (International NGO), CYNGO (country wide NGO), SNGO (Southern NGO) and so on (Green & Mathias 1997). This can make it difficult to get a sense of what type of organization is being discussed. Smilie (1999) makes this point well:

Describing NGOs is like describing cars on a highway. Some are old, some are new. Some have a great deal of baggage, while others travel light. Some are large, some are small. Some of the smaller ones are faster, more efficient and more dependable than the biggest, and cost is not always a factor. Most importantly, all of them are moving and a snapshot of the highway today will be different from a snapshot of the same location tomorrow. (Smillie 1999: 8).

A different type of distinction is sometimes made between spheres of activity so that NGOs are divided between those that advocate for vulnerable or poorly represented groups, those with a more overtly activist agenda (e.g. NGOs promoting the conscientization movement in Latin American) and those that have a mandate for service provision. The distinction is also made between first, second and third

generation NGOs that undergo an evolution from relief and welfare, through small scale self reliant local development to sustainable systems development. In reality NGOs often have a number of ongoing activities, each one of which may be at a different stage of development and sustainability (Korten 1987). Health sector NGOs, for example those working in HIV/AIDS may provide welfare and health services, advocate for vulnerable individuals at the local level and act as political activists in policy circles.

A final interesting point is made by Hilhorst when she notes that whilst considerable effort has been expended upon developing definitions of NGOs and in particular what is 'non-governmental' about them, little if any has been written about their organizational structures and processes (Hilhorst 2003: 2). She argues that NGO is a label that some organizations choose to adopt and as such is a '*claim bearing label*'.

The meaning of the label NGO as an organization that does good for the development of others, is not universal and is contested by two other views of NGOs. One of these is political seeing NGOs as extensions of depoliticised neo-liberal development discourse. ...The other view...is a generalized view of NGOs as unaccountable organizations that are primarily concerned with advancing the material well-being of their staff. (Hilhorst 2003: 7).

This is an important point to bear in mind. Whilst NGOs have increased in prominence their status is not universally embraced and they do have critics (Gilson et al 1994, Pearce 2000).

1.3 The Policy Context of Non-Governmental Organisations

1.3.1 Historical antecedents

The precursors of today's Non-Governmental Organizations were the philanthropic, charitable and religious organizations of the Nineteenth Century. The Christian Missionary Societies sent medical missionaries in the wake of empire builders to practise 'clinical Christianity'. As this name would suggest the desire to 'bring light to dark places' was the underlying motivation for much of this work. These missionaries worked in isolation often with limited skills (Fitzgerald 2001). Other voluntary and charitable organizations that emerged during this period were international in scale and had their roots in activism. For example the British Anti Slavery Society was founded in 1838 and the Red Cross with its principles of neutrality and independence dates from 1864 (Oliver 1966, Shirin 1995). War has also played its part with many of today's big international NGOs. For example, Oxfam and Care emerging during the Second World War as a response to humanitarian crisis (Shirin 1995, Black 1992).

In the Indian context, there is a long history of volunteerism dating back to ancient times. This was formalised in the early Nineteenth Century with the Hindu bourgeoisie in Calcutta pressing for the colonial state to carry out religious and social reform. These issue-based organizations spread and by the late Nineteenth Century there were a number of socio-religious organizations including the Indian National Congress. This trend continued into the pre-Independence period with Ghandi promoting voluntary action as the route to Indian development (Sen 1999).

Following independence in 1947, the Voluntary Health Association of India (an umbrella organization) played and continues to play a significant role in the

development of health care and policy throughout India, the geographical location of its headquarters - within the Ministry of Health and Family Welfare - attesting to its close ties with government. The National Health Policy of 1983 recognised their role formally and assigned them a role as partners in the delivery of services at the grass roots level (Mohan & Mohan 1998). Today there are reported to be 32,100 NGOs in India that are eligible to receive overseas funding (Bahree & Stewart 2008).

Against this background, Non-Governmental Organizations were officially recognised in Article 71 of the 1947 United Nations Charter (de Foneska 1995, Clarke 1998) However, it was not until the mid 1980s and 1990s that they began to rise in prominence. NGOs have increasingly acted as contractors for official aid and development programmes providing services once considered the provenance of the State (Helmich 1999, Palmer et al 2006). Significantly, there has been a corresponding rise in the ability of NGOs to access decision makers and for decision makers in turn to seek out NGO 'partners'(Edwards and Hulme 1998). There has been a rise in government funding in recent years with money formerly channelled through bilateral government programmes going directly to NGOs instead, within both donor and recipient countries (Smillie 1999). There has also been a marked increase in the propensity of multilateral and bilateral institutions to collaborate with NGOs and to channel aid through them. (Lorgen 1998).

This heightened status is exemplified by the inclusion of NGOs in national and international policy forums and the commitment of international institutions such as the World Bank and the UN to working with them. For example the International Development Targets for Health explicitly identify a role for NGOs (DFID 2000). International conferences and global summits have NGO streams and both

governments and international organizations are willing if not positively eager to develop a dialogue with representatives from this sector (McCoy & McCully 1993, Eade 1997, Edwards and Hulme 1998). This transformation in the status and visibility of NGOs has been matched by increasing access to funds and a corresponding rise in the number, size and distribution of NGOs (Shirin 1995, Gellert 1996). Some authors go so far as to describe NGOs as a third sector working along side the state and private sectors and exemplifying the best qualities of both (Salamon 1994). However once again this is hotly contested in other quarters (Uphoff 1998).

1.3.2 The New Policy Agenda

Central to this ever-increasing role for NGOs has been the New Policy Agenda (NPA) that emerged following the collapse of communism in the late 1980s (Eade 1997). This has influenced the political and economic ethos of both governments and key international institutions such as the International Monetary Fund and the World Bank. The term 'Washington Consensus' has been coined to denote the shared ideology of these two institutions and the US state treasury (Stiglitz 2002). Two key trends characterise the NPA despite some variations in detail from country to country and from institution to institution. First, primacy is given to markets and the private sector in achieving economic growth and delivering public services with economic liberalization being the order of the day (Edwards 1994). Second, there has been a call for 'Good Governance', which is in essence democratic government (Edwards and Hulme, 1996: 961).

The New Political Agenda underpinned official aid in the 1990s (Edwards 1994). Within this discursive space, NGOs are constructed as being more efficient and cost effective service providers and better able to reach the poor and socially

marginalized than either the private or public sectors. As Edwards and Hulme succinctly put it:

NGOs (especially the church) have long provided services in health and education, but this was usually by default rather than design...In the New Policy Agenda NGOs are seen as a preferred channel for social welfare and this is a fundamental change. (Edwards and Hulme 1996: 961).

This view is shared by La Fond who notes that ‘economic values in particular [have] filtered into the health sector in an implicit preference for private sector solutions...’ (La Fond 1995: 24-25). Further, with the good governance agenda, a role has been mapped out for civil society both in representing the views of ‘the people’ and in holding governments to account. NGOs are seen as playing a significant role in a thriving civil society and they are believed to act as a counterweight to state power (Edwards and Hulme 1998). Fisher, a strong proponent of the role of NGOs in promoting good governance states:

NGOs strengthen the institutions of civil society that mediate between the individual and the state, both on their own and in conjunction with governments. This in turn can promote increased governmental responsiveness and accountability. (Fisher 1998 :2.).

1.3.3 Globalization

The term globalization is used widely and in lots of different ways. Buse defines it as “(a) complex set of processes which increase interconnectedness and inter-dependencies between countries and people” (Buse et al 2005: 137). Scholte defines it as “a still on-going process whereby the world is in many respects becoming one relatively borderless arena of social [and economic] life” (Scholte 1997). Stiglitz defines it thus:

...(I)t is the closer integration of the countries and peoples of the world which has been brought about by the enormous reduction of costs of transportation and communication, and the breaking down of artificial

barriers to the flow of goods, services, capital, knowledge, and (to a lesser extent) people across borders. (Stiglitz 2002: 9).

The first two authors both use the word 'process' and in doing so highlight the ongoing, dynamic and inevitably changing nature of the term. All three authors emphasize the changing nature of communication across borders, the essential change in the *connectedness* of people and societies with Scholte emphasizing the social dimension and Stiglitz the economic.

Despite the common ground in these definitions, the term 'globalization' is one that is very much context dependent (hence Stiglitz, an economist, foregrounding trends relating to economics and trade) and the way in which it is employed causes a lot of disagreement. This is not surprising given the rapid pace of change in its utilization:

Globalization was initially understood as a purely economic phenomenon, associated with rapid flows of capital, the growth of global corporations and extreme global inequalities. Increasingly though the political, social and cultural dimensions of globalization are being discussed.... (Kickbusch & de Leuw 1999: 1-2).

As the preceding quote suggests, there is also considerable disagreement about whether it is a good or a bad thing (Buse & Walt 2000). What is impossible to ignore is the fact that the manner in which countries have co-operated to address problems of health in general and, more specifically in the context of this study, public health have changed beyond recognition in recent years. The following section will examine these changes in more detail and consider what relevance they have for this study.

1.3.4 Global Public Health

Buse et al (2005) provide a useful schema for distinguishing between the traditional ways in which states co-operated with each other over matters pertaining to health and the modern ways in which this co-operation occurs. In the former there are three

distinct groupings, each with strong state representation, namely the United Nations System, The World Trade Organization (TRIPS) and bilateral development agencies such as Britain's Department for International Development (DfID). In the world of global public health in addition to those listed above there are a number of groupings and coalitions – which, by their very nature, transcend national boundaries. Thus global civil society, Transnational Corporations and global public-private partnerships have entered the mix with varying degrees of power, and importantly, accountability.

Kickbusch and de Leeuw (1999) encapsulate the debate surrounding public health at the global level thus:

It reflects on the balance between national and international responsibility for public health, revisits the mandate of international organizations, the social responsibility of private companies and the role and legitimacy of non-governmental organizations. (Kickbusch & de Leeuw 1999: 1).

They identify two trends evident in the current system of co-operation at the international level, first an increase in the number of players and second the erosion of the sovereignty of states. This is the result of a number of factors namely; the actions of transnational corporations, The IMF setting conditions, the World Bank's efforts at reforming health care, the priority setting of international aid agencies and agreements made by the World Trade Organization and the European Union (Kickbusch & de Leeuw 1999). The authors suggest that global public health could aim to fill the governance gap:

...we could define global public health as the collective ability to conduct healthy public policy at a global level through a network of public, private, non-governmental, national, regional and international organizations by regime formation. (Kickbusch & de Leeuw 1999: 4).

Paralleling this trend in public health governance, the latter part of the twentieth century has seen the emergence of a number of public health threats that also transcend national borders. These include the (re)-emergence of infectious diseases (HIV being the example *par excellence*), environmental degradation and climate change. Many of the defining characteristics of globalization, whether it be the mass migration of workers seeking employment, the ability of people to fly around the globe (potentially spreading disease and damaging the ozone layer), rapid urbanization and so on have all contributed to these health threats. As Parker notes;

Like most aspects of contemporary life, this range of key public health problems has been increasingly impacted by processes associated with globalization. (Parker 2006: 1).

Against this background, it is inevitable that a broad coalition of actors (other than the traditional state led ones) has picked up the mantle of tackling threats to global health, and that what was formerly 'international health' has now be re-framed as 'global health' (Parker, 2006). The following section will look at the changing fortunes of the World Health Organisation (WHO) and the World Bank as a means of illustrating the reality of the situation as described above and considering the space opening up for NGOs.

1.3.5 The World Bank, health policy and NGOs.

In the years following World War Two, WHO took the lead in setting standards, providing technical advice and assistance on medical matters and advocating for changes in health policy (Godlee 1994b: 1491). Operating on a comparatively small budget, it worked within Ministries of Health alongside governments in an advisory capacity. Its focus was largely bio-medical with vertical disease eradication programmes and the deployment of new drugs, vaccines and pesticides. Critically as

a part of the UN system its constitution recognised the internal sovereignty of states (Buse et al 2005).

By the mid 1970s, confidence was wavering in these technologies and the WHO launched the Primary Care Movement as a way of drawing attention to the structural factors that impact upon the health of individuals and societies. NGOs were identified as playing a key role in this new approach to health. However by the mid 1980s, a 'crisis of confidence' had developed within WHO (Godlee 1994a: 1427). The organisation's funding base also changed with an increasing amount of funding being ear-marked for specific programmes (Walt 1993). With a gradual erosion of WHO's position, the World Bank stepped into the policy vacuum (Zwi 2000). Consequently economic institutions are now setting the agenda and driving health policy across the globe (Zwi 2000).

The World Bank did not begin direct lending for health services until 1980 (Walt 1994). However, within a short time, it became the largest single external financier of health in the Developing World making it an extremely powerful player (de Beyer et al 2000). The manner in which the World Bank and its sister organization the IMF have become embedded in the economic re-structuring and lending of money to Less Developed Countries gives them a leverage that WHO could never have envisaged when it comes to 'advising' developing countries on how to finance health and what to finance.

As one might expect, the World Bank views health as an economic commodity (De Beyer et al 1997 cited in Walt & Buse 2000: 177). This had led to the erosion of the principles of social justice and equity in the provision of public health (Poku 2002). This is in line with the economic imperatives of the New Policy Agenda. Health services and public health are viewed as a 'financial burden on governments which

should be avoided' (Poku 2002: 191) rather than the cornerstone of a productive and healthy population and as a basic human right.

Second, the role of the state has been undermined with respect to setting standards for public health policy. The actors who now take a key role in public health policy and health care policy are to a large extent unaccountable. For example in 2002 The Bill and Melinda Gates Foundation (BMGF) invested US\$ 200 million in HIV prevention in India (Ramakrishnan & Alexander 2006). Further, the rise in public private partnerships (PPPs) and the contracting out of services once considered to be the provenance of the state has put a new set of actors in key positions of authority. The question of accountability and legitimacy within NGOs is also a matter for concern (see section 1.4.3).

1.3.6 How do NGOs feature in this?

The World Bank established an NGO unit in 1988 (Smillie 1999). By 1996 there had been a significant rise in NGO involvement in World Bank projects with an estimated 48% of projects including NGOs in some capacity although the extent of this involvement is difficult to gauge (Smillie 1999). Given that the Bank has become the biggest single donor to health care projects in the developing world in recent years, its approach to NGOs is of no small consequence. The Bank's favourable opinion of NGOs as health care providers can be seen in its 1993 World Development Report, *Investing in Health* (The World Bank 1993). This calls for competition in health care provision and places particular emphasis on the involvement of NGOs. 'This call like its predecessors is based on the expectation that NGOS have significant advantages over government in the provision of health care' (Gilson et al 1994: 14).

1.4 NGO performance: the substance behind the rhetoric

1.4.1 What do health sector NGOs actually do?

Given the clear policy preference for NGO involvement in the health sector, it is important to establish what NGOs actually do. In practice, NGOs working in health undertake a wide range of activities. Green & Mathias (1997) identifies seven areas of activity, namely service provision, research activities, provision of support services, policy advocacy, fund-raising and co-ordination. Gilson et al (1994) similarly identifies service provision, social welfare activities, support activities (for example the training of health care workers or supplying drugs), research and advocacy as key NGO activities. As she notes:

NGOs are therefore not only providers of health care but also community activists, managers, trainers, development workers and international lobbyists. In all these roles, what ever their size or nature they make an important contribution to the health sector. (Gilson et al 1994: 16).

Increasingly then, NGOs are presented as having the ability to tackle complex health problems in situations where both the public and private sectors have failed to achieve lasting improvements and reforms. This may entail forming a Public Private Partnership between the state and the private sector (including NGOs) for example to help diagnose and treat TB (Dewan et al 2006), delivering a range of services to a distinct community such as tribal women in West Bengal (Mohan & Mohan 1998), or indeed competitively tendering to provide health services at the district level in a 'fragile state' (Palmer et al 2006).

1.4.2 Addressing the political dimension

Given that the emerging role for NGOs, as illustrated above, cuts across the traditional purview of the state, it raises difficult issues around sovereignty. There is an undeniably political element to the work of NGOs (Hilhorst 2003). This can also

be seen in the work of NGOs whether this entails providing a safety net to counteract the effect of structural adjustment, revitalising political participation and social movements or providing links between citizens and governments.

Clarke argues that 'NGO activity is intrinsically political' which begs the question of why there has been such a weak political dimension to NGO literature (Clarke 1998). He offers the following reasons. First, much of the literature is donor-driven (whether conducted by social scientists or NGO activists). The political dimension of this work may be of no interest - or it may be deliberately ignored. Second, funding restrictions on Northern NGOs prevent them from undertaking work deemed as straying into the sphere of politics. Third, donors may be reluctant to publicly acknowledge that they are funding NGOs as a means of strengthening opposition to authoritarian regimes. Fourth, donors favour social development activities thus overlooking the more overtly political characteristics and activities of NGOs (Clarke 1998).

This combination of factors has led to what Clarke describes as 'an inadequate, explicitly normative, interpretation of NGO ideology' (Clarke 1998: 40). Thus liberals describe NGOs as a 'third sector' combining the best of the public and private sectors. Neo-liberals see NGOs as part of the private sector, able to deliver services to the poor cheaply. Left wing intellectuals and activists see NGOs as representing a 'new politics' (Clarke 1998: 40). However, as was noted earlier not everybody accepts the idea of the increase of NGOs as unfailingly good and there is an increasingly critical edge to the literature (Pearce 2000, Mageli 2005).

1.4.3 Legitimacy and accountability

NGOs are often criticised for their lack of legitimacy and their non-accountability. These are complex issues. NGOs need to be able to work with the state, both in terms of observing legal restrictions but also as a means of advocating for their work and representing the 'voice' of their constituents. Clarke asserts the fact that NGOs can 'oppose the state, complement the state or reform it, but they cannot ignore it' (Clark 1991: 75). The New Policy Agenda with its emphasis on good governance is premised upon the belief that NGOs are part of an active civil society will be able to act as a counter balance to state power and hold it to account. Correspondingly strong government is a pre-requisite of the NPA (Edwards & Hulme 1998).

Implicit in some of these views is the idea that NGOs counter, but do not seek to replace the state. In practice, however, the wider process of globalisation (whereby state sovereignty has been eroded) has resulted in a significantly extended role for NGOs. As Lorgen (1998) predicted, donors may side-step governments altogether (further weakening the legitimacy of the state) or governments themselves stop thinking that they need to provide services. As a result, NGOs find themselves 'stepping into the shoes of the state' (Lorgen 1998: 327). This has a number of important consequences. Philosophically, it undermines the emphasis (associated with the strong welfare state) on health as a universal right and on the state's responsibility to provide for the health needs of its population. Practically, it undermines the promotion of equity. Because NGOs lack the oversight, budgets and decision-making power to ensure that health services are available to all, relying too heavily on the non-governmental sector results in a 'patchwork quilt' of services (Edwards 1994). Thus, it can be argued that weaknesses and failure in state

provision are not in and of themselves a justification for the retreat of the state and its replacement by NGOs.

With regards to accountability, the majority of NGOs are ultimately accountable to their boards of trustees. They have some legal obligations to fulfil and some requirement to report to their government (Smillie 1999). There is also an increasing interest in NGOs observing their accountability to beneficiaries as a means of proving their legitimacy (Kilby 2006). Therefore, rather than having too little accountability they are faced with the difficulty of being accountable to multiple stake-holders (Edwards & Hulme 1998). Moreover, the reality of the situation is that real power resides with donors. NGOs have an obligation to donors and if this is not fulfilled the donor may withdraw funding (Lorgen 1998). Seen in this light, downward accountability is little more than a 'grace and favour' gesture (Kilby 2006). Against intentions, these lines of accountability do not automatically result in improvements in NGO performance:

The type of appraisal, monitoring and evaluation procedures insisted on by donors, especially their heavy reliance on 'logic framework' approaches and bureaucratic reporting, may also distort accountability by over emphasising short-term quantitative targets, standardising indicators, focusing attention exclusively on individual projects or organizations, and favouring hierarchical management structures. (Edwards & Hulme 1998: 13).

Much of this militates against the types of long term, adaptive and nuanced work for which NGOs are praised. This is particularly so where the inherent value of their work - whether it is the creation of trust, intra-community co-operation, or empowerment - is difficult to define and harder still to measure yet nonetheless is believed to be beneficial to communities and to individuals within communities. The activist agenda of NGOs may be effectively silenced if the focus on measurable

outputs takes precedence (Smillie 1999). In this climate the danger of co-option is an ever-present threat for NGOs.

1.4.4 NGO Performance: Strengths and Weaknesses

Another important issue concerns the performance of NGOs. While the enhanced status of NGOs has been welcomed in many quarters, others question whether NGOs are actually able to deliver what is expected of them. In reality, literature that critically evaluates the work of NGOs, their strengths and weaknesses, successes and failures is in short supply and it is rare to find rigorous comparative research (Edwards & Hulme 1996). The literature that does exist has a tendency to describe NGO projects and programmes in an uncritical way rather than to evaluate them. Much of this work comes from within the NGO or development community, or from NGO sponsoring organizations, and is circulated as grey material or to a lesser extent in the NGO stream of conferences (Clarke 1998: 39). Detailed ethnographic case studies rather than comparative studies seldom find a publisher (Hilhorst 2003). A knock on effect of this is that grassroots NGOs can experience extreme difficulties in getting their voices heard by international policy makers and funding sources, despite the rhetoric about partnership and participation (Porter et al 2004).

1.4.4.1 Cost-effectiveness

Foremost amongst the perceived strengths of NGOs, is the belief that they are more cost effective in delivering services to the poor than the state sector (Korten 1987, Gellert 1996, Edwards & Hulme 1998). The World Bank promotes NGOs on the basis that they are the most efficient service providers and that they are also able to provide higher quality services than either the public or private sectors (World Bank 1993). For instance, it is suggested that NGOs are less bureaucratic and that they

have fewer overheads than statutory bodies (Shirin 1995, Smillie 1999, DeJong 2003). The major expense of salaries is reduced through the mechanisms of recruiting volunteers and paying salaries lower than the market rate. NGOs have also proved to be highly innovative in approaches to financing, many charging user fees for their services (Dave 1991).

Others, however, argue that the perceived cost-effectiveness of NGOs is countered by key disadvantages, not least the danger that user fees make services inaccessible to the poorest of the poor (see below) (Xu et al 2006). Similarly, while it is certainly the case that some NGOs pay lower salaries than the private or state sectors, it can equally be argued that, in order to attract the best employees, particularly in key positions, a competitive salary package must be offered (personal communication – Oxfam UK).

More problematically, the reality for supposedly 'cost-effective' NGOs is that they experience considerable problems in managing their day-to-day operations because of a vulnerable financial base (Gilson et al 1994). Many of these problems stem from the funding priorities of international donors. First, there is a tendency for funding to be project specific. International donors favour discrete projects and will cherry pick the projects that they want to fund with clearly ring-fenced grants. However, their 'partner' NGOs in the developing world may develop an integrated programme that does not lend itself to being divided into discrete sections for the purpose of funding. This means that NGOs lose the ability to set their own priorities and may have too little funding to maintain their programmes as a whole. Correspondingly they can experience difficulties spending ring-fenced money in the allotted time leading to wasting money (Smillie 1999).

Difficulties can also arise through the need to meet core organizational costs and administrative overheads (Smillie 1999). This is exacerbated by the fact that funding is often only available for a limited period of time (Stefanini 1995). For example, the funding cycle may be only two years or less or funding is only made available for start up costs. This leaves NGOs in a constant process of applying for money or looking for alternative sources of money (Gilson et al 1994). Several factors make this task more difficult. At the end of a funding period, the priorities of the donor may have moved on. Gaps between funding cycles also hamper sustainability. Here, well-established projects may grind to a halt for a few weeks or months during which time trained employees leave and project users drift away. When the funding re-commences the whole start up process has to begin over again (Smillie 1999). This is not only a considerable waste of time and money. It can significantly compromise trust with project users (Gilson et al 1994).

A major consequence of this uncertain financial base is that NGOs spend much of their time fund raising. A commitment to delivering discrete project elements that are funded by donors means in reality that less time may be available for other activities such as influencing the policy agency and garnering public support. Against this background, the funding and campaigns departments of major international NGOs are often at logger-heads about how their organisations can strike the right balance between competing priorities (personal communication Oxfam UK, Smillie 1999).

1.4.4.2. Reaching the poorest of the poor

Another claim made for NGOs is that they can reach the poorest of the poor in areas of greatest need (Gellert 1996, World Bank 1996, Feeney 1998, Kilby 2006). This is proffered against a background of stringent cost-cutting and the reduction in state provision within the developing world. If this is true then it certainly strengthens the argument for developing the role of NGOs. Edward and Hulme (1996) suggest that there is some evidence to support the claim that they are better able to reach poor sectors of society than the state sector. However, they temper this by saying that 'claims that NGOs reach the 'poorest of the poor' are often inaccurate...' (Edward & Hulme 1996: 963). In reality this is very difficult to measure and is often wide of the mark (Clark 1991).

Nonetheless the notion of 'service to the poor' is important for NGOs because this provides the ideological basis for their work and their claim to legitimacy (Hilhorst 2003). It is difficult to argue with the *modus operandi* of an organization whose stated aim is to alleviate the suffering of the poor. Many actors in the development sector accept that service to the poor is their primary motivation (if not the sole motivation) with little comment. Although it is not universally accepted as was noted in section 1.4.2.

Certainly at the individual level the desire to serve the poor may be a factor in the willingness of individuals to work for lower salaries or to volunteer (Mercer et al 1991, Clark 1991). However, this faith in the altruism of NGOs can at junctures take on a somewhat idealised and uncritical tone. Some NGOs do operate as 'for profit' organizations, charging user fees for their services. Others may have an underlying mandate to proselytise - for example the Catholic Church (Gilson 1994). This

suggests that the motivation of NGOs is less clear-cut than much of the literature suggests.

One reason given for why NGOs are able to reach the poorest of the poor is that they are often created and staffed by community members. This, it is argued, affords them unique insights into the problems of a given community and may facilitate trust – perhaps opening up the way to help transform beliefs and behaviours (Chambers 1997). However, this needs to be examined on a case-by-case basis. As has already been stated NGOs differ in many respects from Community-Based Organizations, Grass Roots Organizations and popular movements not least in terms of their composition, membership and accountability. An NGO may be physically located within the community with which it works; it may employ members of the community or use volunteers from within that community. But then again it may not. None of these things is a given. In reality the decision making power will lie with the board of trustees as one author puts it ‘a collection of the great and the good’ often far removed from the community (Edwards & Hulme 1996). Health NGOs will often have a doctor as their director, who may originate from within the community- but then again may not! The building of a close relationship with community served may take a long time and be continually in a state of flux (Mageli 2005).

Three lesser points are also worth noting. First, within organizations with a culture of volunteerism there may be a heavy reliance upon a charismatic leader. This can affect sustainability and replicability (Clark 1991). Second, when considering the human side, attrition and burn out are a significant problem. This is particularly true where volunteers rely upon stipends to get by or where salaries are very low, or indeed where training and professional support are in short supply. There can be a

downside to this culture of volunteerism, particularly with relation to health where no amount of good will compensate for a lack of adequately trained, qualified, supported and regulated personnel. Finally NGOs may believe in the inherent value of their work and correspondingly that training, evaluation, research, dissemination of findings through publications and seminars are unnecessary (Smillie 1998).

1.4.4.3 Cooperation and inter-organizational working

A significant problem is the ability or willingness of NGOs to work with one another or with other sectors. As Green and Mathias note:

Whilst it is of course poor management for any organization to ignore the external environment and in particular other organizations occupying similar strategic space, this is particularly so in the health sector. (Green & Mathias 1997: 120).

The ability to work collaboratively with other actors in the health sector is particularly important and can be a real challenge for NGOs. The NGO sector itself is 'internally competitive' which militates against cooperation (Moore & Stewart 2000: 85). Pearce reiterates this when stating that the 'real world' of development NGOs is 'characterised by mistrust and by fierce competition over resources...' (Pearce 2000:16). At the state level, civil servants and politicians may be at best ambivalent towards NGOs (Green & Mathias 1997). The reality for many NGOs is that their relationships with other actors are characterised by antagonism (Edwards & Hulme 2000).

This is a cause for concern because NGOs working in health need to know when, where and how to refer patients, how to access government reporting systems for notifiable diseases, how to access the government resources available (for example for TB medication) and so on. In reality NGOs often struggle to do so and may well be blocked in their attempts by un-cooperative state-level actors. Similarly, whilst

much is made of the power of civil society and the coalitions of NGOs many NGOs, working in a vulnerable financial environment see other NGOs as competition for scarce resources. Allied to this NGOs are playing an increasing role in the control of infectious diseases and it is important that they are able feed back up the policy process. More attention needs to be played to the role that NGOs can play in policy transfer and means by which they can be supported in doing this (Porter et al 2004).

1.4.4.4. Technical and managerial issues; capacity building and sustainability

Whilst NGOs may be less bureaucratic than the state sector and more flexible in their modes of operation, allowing them to act quickly and innovatively, a number of factors undermine the ability of NGOs to fulfil the expectations of their donors. Many NGOs lack skills in planning and management, robust information systems and see only a small part of the problem. Many are small or work within limited geographical areas. Thus, they cannot possibly have oversight of the entire health sector and cannot offer national coverage or uniformity (Edwards 1994, Clark 1991). Capacity building and sustainability can also be hugely problematic. Thus, many organisations cannot guarantee that services available one day will be available the next because of a precarious funding base (Lorgen 1998). This raises two points. First it has been argued that sustainability for health sector NGOs should involve support for the government sector to build up district level health services (Stefanini 1995). This is because the NGO sector can never replace the state sector but it can enhance it. Examples of this can be seen in India where NGOs are integrating TB and leprosy services into state level services (Porter et al 2002, Porter et al 2004). Second, sustainability would be greatly enhanced by the sort of long-term donor commitment that was flexible enough to meet re-occurring costs and to continue after the end of programmes (Stefanini 1995). Kilby (2006) in his study of NGO

accountability found that the flexibility of donors with respect to funding was the one factor that increased downward accountability.

1.5 Conclusion

This chapter has explored the emerging role for remove NGOs working within resource poor settings and within the context of global public health. There has been an exponential rise in the number of NGOs working in health in recent years. Increasingly international donors are choosing to channel their funds directly to NGOs rather than through the state. NGOs are presented as a panacea to the problem of delivering cost effective health services within resource-poor settings. It is suggested that they offer better value for money than the public sector and have a greater capacity to reach the poorest of the poor than either the public or private sector. This is particularly important at a time of crisis within the global public health community with the (re)-emergence of infectious diseases undermining previous advances in life expectancy.

However, whilst policies at the global level strongly advocate the use of NGOs and are spearheading new and challenging means of incorporating them into the public/private mix, it is important to understand why this development has come about. The rise in the ascendancy of NGOs can be traced back to the political and economic ideology of The New Policy Agenda that emerged during the latter half of the 1980s following the collapse of communism. This New Policy Agenda was premised upon two beliefs. The first is in the primacy of markets in delivering services once formerly considered to be the role of the state. As such, health becomes a commodity to be bought and sold rather than a fundamental human right. With market failure a feature of health service delivery in the private sector NGOs

have assumed a key role in offering an alternative to state sector involvement. Second the governance agenda placed civil society (of which NGOs are a key constituent in policy circles) at the heart of the political reform of failing states (Edwards and Hulme 1996).

Having opened up this space for NGOs, the emergence of the phenomenon of globalization has also had a significant impact. The balance of power in health policy has shifted from the state level to the global. The traditional players in international health, for example the WHO and bilateral development agencies (for example DFID) recognised the sovereignty of the state (Buse et al 2005). However, the new players in what has been re-inscribed as 'Global Public Health', from the World Bank, to multinational corporations and international coalitions of individuals and civil society are less accountable to the state (Kickbusch & de Leeuw 1999). NGOs offer the means for these external actors to redesign health policy at the global level and implement it locally, in many instances completely sidestepping the state.

Given this dramatic shift in a relatively short period of time it is vitally important that the reputed strengths of NGOs, over and above those of the state, are held up to close scrutiny. It is argued that NGOs are both more cost effective than the state (Korten 1987, Gellert 1996) and more able to reach the 'poorest of the poor', those least able to access the private sector (World Bank 1996, Feeney 1998, Kilby 2006). However, firm evidence to support this is hard to come by. In reality, NGOs suffer from extreme funding problems. These can result in irregularly funded donor driven projects that stop well short of the lofty aspirations set for them. Further, there are many incidental costs around the development, support and training of NGO projects that are not reflected in their accounts.

An associated problem is of the volunteer culture within NGOs that can translate into amateurism in service delivery. This presents a real challenge for health sector NGOs if they are to offer services that can stand up to professional standards of scrutiny and accountability. Finally, the incorporation of NGOs into the machinery of global public health leaves them open to the accusation of co-option and the risk of sacrificing their activist credentials for the pursuit of lucrative, but short term, contracts for service delivery (Shirin 1995, Edwards & Hulme 1998, Cannon 2000).

The overarching narrative of a 'third sector' (implicit if not explicitly stated in much of the discussions around NGOs) whilst offering a totalising account of unquestioned success and superiority to other sectors, airbrushes out the tensions, contradictions, and weaknesses inherent within many NGOs. As such it offers a distorted picture of current success and creates unrealistic expectations for potential growth and development. This should raise alarm bells for policy makers involved in designing policies for the prevention and control of HIV, which rely heavily, if not almost exclusively, upon NGOs. Against this background the next chapter will look at NGOs, global public health policy and HIV/AIDS.

Chapter 2

HIV/AIDS programming in resource-poor settings

2.1 Introduction

This chapter is concerned with a specific public health problem, HIV/AIDS. It will explore the global response to HIV/AIDS and the dominant themes within global guidelines for prevention and control and care and support. In doing so, it will map out the ways in which a role has been created for NGOs in the implementation of HIV/AIDS related policy and programming within the context of resource-poor settings. This role is based upon the belief that, within such contexts, NGOs will be able to identify and work with those at greatest risk of contracting the virus because of their existing links with vulnerable communities (Mann & Tarantola 1996).

The latest figures released by UNAIDS and WHO (2008) on the global epidemic report that an estimated 33.0 million people are living with HIV worldwide. In 2007 2.7 million people contracted the infection and 2.0 million people died of AIDS¹. This gives a clear indication that the problem of HIV/AIDS remains a serious one. Despite these figures there are indications that some countries have seen a reduction in the number of new infections. For example, the most recent figures from UNAIDS on the global pandemic suggest that Rwanda and Zimbabwe have reduced the number of new infections (UNAIDS 2008). Furthermore it is important to remember that the global pandemic is made up of multiple overlapping epidemics that vary both within and across countries (Mane & Aggleton 2007). This can make it difficult accurately to represent the problem at the country level. Against this background there has been a significant increase in the HIV prevention efforts aimed

¹ These figures are updated every other year.

at commercial sex workers, men who have sex with men and injecting drug users, the so called 'core transmitter groups' (UNAIDS 2006).

The chapter will begin with an overview of the HIV/AIDS pandemic and the development of a global response to it. It will then explore biomedical discourses of HIV/AIDS. These biomedical discourses are important because they have been the dominant voice in explaining the pandemic in terms of high risk groups and high risk behaviours and in setting the parameters for how prevention and control strategies have been designed. As Waldby states:

...biomedicine has successfully established its right to represent the real of the disease, its irreducible materiality. Biomedical knowledge has the greatest legitimacy in the field and can effectively set the terms that other discourses must observe. (Waldby 1996.5).

It will be argued that the biomedical and behavioural approaches to HIV prevention arising from these discourses, have limitations when applied within resource-poor settings, as indicated by the emergence of a developmental model focusing on high risk situations in the early 1990s (Zwi & Cabral 1991). The second part of the chapter will consider the strategies for prevention and control that have emerged from the evolution of these two approaches to the HIV/AIDS pandemic. In doing so it will highlight the role identified for NGOs. The third section will look at the issue of care and support for those infected/affected by HIV/AIDS and how this intersects with a human rights based approach to the pandemic. This is a complex and rapidly evolving area and raises a number of issues for NGOs.

2.2. HIV: a global pandemic and a global response

2.2.1 HIV and its identification as a pandemic

The first reported cases of what would later become known as AIDS, emerged in gay men in the USA. The June 5th 1981 edition of Morbidity and Mortality Weekly Reports carried a report of pneumocystis carinii pneumonia in five male homosexual patients (Cited in Schoub 1999). This was the forebear of a rapidly escalating health crisis. In the absence of an explanation for what was causing the illness, the U.S. gay community began to work collectively to promote strategies for safer sex, provide support and care to those affected, to lobby for funding to research into the illness and to campaign against the discrimination that was inimically bound up with AIDS from the outset (Shilts 1988, Weeks 1989). The first name given to AIDS was GRID (Gay Related Immune Deficiency). However, cases of the syndrome were increasingly reported in heterosexuals, clearly indicating that it was not restricted to gay men. Similarly cases were emerging from different parts of the world suggesting that it was a problem of global scope. For example, cases of Karposi's sarcoma were diagnosed in Africa in 1983 (Downing et al 1984, Bayley 1984).

Scientific research made huge strides in the early years of the pandemic. HIV was identified in tissues from people with AIDS in 1983. There was rapid progression to the development of simple laboratory tests for identifying antibodies to the virus, enabling a laboratory diagnosis of HIV infection to be made (Kallings 2008). Second, doctors developed criteria for diagnosing AIDS and developed expertise in treating the opportunistic infections associated with the syndrome (Piot et al 1988, WHO 1996). Third, epidemiologists identified three patterns of HIV infection to help guide the policy response (Man & Kay 1991).

Notwithstanding these scientific advances the arena of AIDS research has been fraught with conflict and uncertainty. As Epstein notes:

From a scientific standpoint, the sheer complexity of AIDS has ensured the participation of scientists from a range of disciplines, all of them bringing their particular, often competing, claims to credibility (Epstein 1996:3).

Biomedicine can be understood as a descriptive category within which other scientific disciplines are located. As Epstein (1996) states, the complexity of AIDS ensured that scientific researchers from different disciplines were involved including clinical medicine, epidemiology, virology and immunology. Thus debates and disagreements have characterised the ongoing process of AIDS research both within and across these sub-disciplines. For example, the identification and naming of HIV was fraught with conflict with two research teams both vying to be recognised as the first to identify the virus (Patton 1990). Nor was the causal link between HIV and clinical AIDS accepted by all scientists. The so-called 'AIDS doubters' continue to challenge the connection between HIV and AIDS and this position has informed national level policy making for example, until recently in South Africa (Shenton 1998, Goldacre 2009). Similarly early criteria for diagnosing clinical AIDS were challenged on the grounds that they failed to incorporate clinical symptoms found in women, children and individuals within developing countries (Piot et al 1988, Openheim 1994). This led to new diagnostic criteria that are context specific and engage with these different populations. Similarly there are differences of opinion about the appropriate point at which to commence Anti Retroviral Therapy (ART) and whether starting early with treatment confers long term benefits that override the problems associated with these drug regimens (Kallings 2008).

The development of global guidelines for best practice needs to be understood within this context. Walt et al (2004) highlight the manner in which the transfer of

these policies from the international to national levels is the final stage in a long process:

...health policy transfer is a long adaptive process, made up of several iterative loops, as research and clinical practices developed in one or more countries are adopted, adapted and taken up by international organizations which then mobilize support for particular policies, market, and promote them (Walt et al 2004:189).

This process involves active engagement between different research and policy communities. These communities are dynamic, with changing membership and may move between consensus and conflict.

In addition to these debates about scientific understandings of HIV and aspects of clinical care there have been ongoing disagreements about the approaches to be taken to prevention and control (Kallings 2008). These have taken place again both within, and across, disciplines and have often coalesced around the issues of confidentiality and human rights. The right of individuals to choose to undergo a HIV test and their right to confidentiality were virulently questioned in the early days of the pandemic, with calls for enforced testing and quarantine, of those found to be infected being proposed as policy options (Shilts 1988, Garfield 1994). Thus, whilst biomedicine may lay claim to being value neutral the meanings brought to bear on HIV/AIDS have been anything but. Biomedicine needs to be understood as a cultural practice, one amongst many. Persson et al (2003) highlight this when they say that:

[biomedicine's] claim to truth and objectivity obscures the ideological and political investments of medical knowledge as a situated knowledge... (Persson et al 2003:401).

Against this background the following section will discuss the emergence of a global response to HIV AIDS.

2.2.2 The emergence of a global response to HIV/AIDS

At the policy level, the first International Conference on AIDS was held in Atlanta, USA, in 1985. The following year, the World Health Organization established its Special Programme on AIDS which subsequently became the Global Programme on AIDS (GPA) (Seckinelgin, 2008). At this stage there was a lack of consensus about how big a threat AIDS was likely to become. By June of 1986, however, when the second International Conference was held, AIDS was being described as 'an urgent global health problem' (Mann & Kay 1991: 221). By 1987 the stigma and discrimination associated with the pandemic were recognised by the WHO as having serious implications for attempts at preventing and controlling the spread of the infection. The World Health assembly adopted a resolution in 1987 entitled 'Avoidance of discrimination in relation to HIV infected individuals and people with AIDS' (Mann & Kay 1991: 226). In the early years of the GPA, a number of strategies were developed to assist countries in developing short and medium-term plans based upon epidemiological trends of infection (St John et al 1988). The need for the maintenance of human rights was reiterated throughout.

The active engagement of NGOs was sought with the realisation that national and international responses had their limitations (Mann 1991). This enthusiasm for including NGOs in national level policies can in part be traced back to the pioneering work of gay community based organizations in the USA (Asthana & Oostvogels 1996). The involvement of NGOs has also been a key feature of participatory development since the mid 1980's (Eade 1997). Again a World Health Assembly Resolution helped to focus attention on the important part to be played by NGOs. This emphasised the 'vital and complementary role of non-governmental organizations in AIDS work at all levels' (Mann & Kay 1991: 226).

However, by the late 1980s the GPA was beginning to experience some difficulties. In 'normal circumstances', the WHO worked within Ministries of Health, providing technical advice and support. It did not fund projects and had limited resources at its disposal. The GPA, on the other hand, had a considerable budget but no mechanism to distribute it. This problem was resolved when the United Nations Development Programme (UNDP) took on the role of disbursing funds for the GPA. Inevitably however, given their different mandates and areas of expertise the approaches taken to the pandemic by the UNDP and the GPA were not always the same (Merson et al 2008). This gave rise to a situation where two (or at times more) UN agencies were working in a given country and advocating different approaches to the pandemic (personal communication UNAIDS, Delhi). This of course had happened before with the Primary Health Care Movement (Banerji 1999). In this instance it reflected growing disagreements about how to tackle the problem with some arguing for short-term public health approaches and others for more long-term structural responses (Merson et al 2008), indicating once again that HIV/AIDS was a conflictual field in terms of policy development. Over time, criticisms of conflict of interest and duplication of effort between the GPA and other UN organizations began to be voiced (Nau 1994). Commenting on this situation Garbus notes that:

Historically, efforts to coordinate UN activities in any field have been difficult. Despite agreements on the leadership role of WHO and its relationship to other agencies (e.g., the WHO/UNDP Alliance), coordination on policies, strategies and most crucially on support activities at the country level became increasingly problematic (Garbus 1996: 369).

Furthermore it has been argued that despite the inclusion of NGOs and the recognition of the need to address the pandemic as a problem with a human rights dimension the GPA was 'medically and epidemiologically driven, and adopted a short term and conceptually limited fire-fighting perspective' (Barnett & Whiteside

2002: 74). A change of Director General in 1988 saw a reduction in the budget of the GPA driven by a desire to bring it back in line with other aspects of WHO work. This occurred at a juncture where, a number of other UN organizations had developed an interest and expertise in HIV/AIDS and when, the need to address the social, economic and developmental determinants of the pandemic was becoming increasingly evident. As such it was becoming increasingly clear that HIV/AIDS was having a multi-sectoral impact and necessitated a multi-sectoral response.

2.2.3 UNAIDS: A different form of international response

It was against this background, and in response to the growing pandemic, that a new UN-level programme was proposed that could offer 'a more co-ordinated, comprehensive and expanded response to HIV/AIDS' (Garbus 1996:369). The Joint United Nations Programme on HIV/AIDS (UNAIDS) was established in January 1996. The UNAIDS Strategic Plan 1996-2000 notes that:

...[a] special joint programme, bringing together UN organizations with complementary mandates and expertise, was though to be warranted by the epidemic's urgency and its magnitude, its complex socio-economic roots, the denial and complacency still surrounding HIV and its roots of transmission, and the discrimination and human rights violations faced by those infected or threatened by HIV (cited in Timberlake, 1998: 87)

UNAIDS is both conceptually and structurally different to the GPA. This reflects the need to broaden the approach taken to HIV/AIDS and to work collaboratively within and across multiple agencies and organizations each bringing its own expertise. At the global level UNAIDS was formed as the global AIDS programme of its co-sponsors, namely the United Nations Development Programme (UNDP), the United Nations Children's Fund (UNICEF), the United Nations Education and Scientific Organization (UNESCO), the United Nations Fund for Population Activities

(UNFPA), the World Health Organization (WHO) and the World Bank (WB)². It has a secretariat based in Geneva. At the country level UNAIDS has developed an innovative way of working. It does so through UN Theme Groups on HIV/AIDS. These offer support to governments and the wider community. Theme Groups are supported by UNAIDS Country Programme advisers (CPAs) and Inter-Country Technical Teams. UNAIDS at the country level has been described as 'the joint action and collective resources of the cosponsoring organizations' (Piot 1996: 370). Merson et al 2008 describe this as a 'radical change in the global architecture of multilateral support for HIV work' (Merson et al 2008: 483).

At its inception UNAIDS had four objectives. First, it sought to encourage countries to develop an expanded national response including the development of short, medium and long-term plans. Second, and closely allied to this was the aim of promoting a strong governmental commitment to these national plans, a clear indication of the need for high level 'ownership' of the problem. Third, it aimed to strengthen action on HIV/AIDS within the UN system. Fourth was the aim of identifying, developing and advocating on international best practice (Piot 1996). Because of the structure of UNAIDS, the co-sponsoring agencies take a lead on areas for which they have a particular expertise, always with the aim of mainstreaming and integrating approaches. This new approach has not been without its challenges. Writing in 1996 Garbus pointed out that the six different agencies have different missions, primary clients, areas of expertise, levels of funding and staffing levels. And she predicted that 'Melding the interests and capabilities of these six agencies will be difficult...' (Garbus, 1996: 369). A view echoed by Poku (2002), who notes:

² These have been joined by the United Nations Office on Drugs and Crime (UNODC), the World Food Programme (WFP) and the International Labour Office (ILO).

The complexity of the mandate- getting six agencies whose priorities range from UNICEF's concern for the welfare of children, to the World Bank's preoccupation with development to work in concert was famously described by Mann as comparable to walking six cats on a leash (Poku 2002, 288).

It has also been suggested that co-ordination between UN partners was difficult because none were wholly committed to a joint programme (Merson et al 2008). Barnett & Whiteside (2002) however have highlighted the extent to which UNAIDS' mandate for coalition building, interagency working and co- ordination makes it different from other larger UN agencies, such as the WHO or the UNDP which they describe as being quite autonomous and exercising a high degree of independence within the UN system (Barnett & Whiteside 2002). They explicitly state that UNAIDS could act as a precursor to a new approach to the provision and distribution of international public goods such as primary health care. Finally Seckinelgen (2008), has suggested that UNAIDS as the co-ordinating body for UN related HIV/AIDS interventions, has been instrumental in the formation of a de-facto governance regime for HIV/AIDS including a prescribed role for civil society.

2.2.4 Alternative Voices

As the above would suggest, there is standardization of approach to HIV/AIDS policy within the multilateral institutions of the UN system despite the considerable disagreement within the scientific, academic and policy communities about approaches and understandings of the pandemic (Seckinelgin 2008, Das 2009). Das (2009) suggests that the World Bank has been a dominant voice in this global governance because of its financial strength linked to financial lending requirements for projects (including HIV/AIDS projects) and its capacity to wield 'information power'. This is described as the capacity to promote World Bank understandings of social problems through project design and the dissemination of information at the UN and country level. This also has an effect at the country level:

By identifying issues as social problems and representing them in specific ways through information dissemination, lending requirements and projects, the World Bank significantly influences country policy debates and policymaking (Das 2009: 209-210).

The role of the World Bank in relation to HIV/AIDS policy at the global and national levels has been widely debated (Jessani 2000, Banerjee 1999, Poku 2002, Rowden 2004). UNAIDS itself, has recognised that there is a problem relating to constraints on spending articulated in IMF loan conditions and reiterated by the World Bank in lending for HIV/AIDS projects. This is because these circumscribe the policy options for spending on HIV/AIDS (UNAIDS 2004). However, whilst certain actors may appear to have more power and influence at a given point this should not be taken to imply an easy consensus between multilateral institutions. For example, the World Bank and the UNDP have had an increasingly conflictual relationship since the former moved into the arena of development policy in the mid 1980s (Boas & McNeil 2003). Furthermore Boas & McNeil (2003) highlight the fact that multilateral institutions are also social institutions with social actors and they

are subject to the same internal disagreements as any other organization. Thus there is a need to achieve consensus within these organizations as well as between organizations. Thus the technocratic approach to policy (as opposed to overtly politically driven policy) can be viewed as a necessary precursor for consensus building both internally and externally.

Furthermore, the institutions within UNAIDS are not the only global actors. A number of initiatives have emerged in recent years to try and re-orientate policies, or to better fund and support neglected aspects of them. These include the International AIDS Vaccine Initiative (IAVI) (Berkley 1997) and the Global Fund to Fight AIDS, Tuberculosis and Malaria³ (GTFATM) (Poku 2002, Poore 2004). Bill and Melinda Gates have established a foundation in their name to tackle problems of global public health with a substantial budget. For example, in 2002 they contributed US\$ 200 million to India's National AIDS Control Programme (Ramakrishnan & Alexander 2006).

Other networks, such as the Treatment Action Campaign, campaigned for a reduction in the price of patented essential medicines such as ART (Heywood 2004). Increasing access to the internet, international conferences and the proliferation of networks and umbrella organizations linking NGOS, CBOs and grassroots organizations at the local, national and international levels, all provide opportunities for individuals, organizations, activists, academics, health care professionals and people living with HIV/AIDS to share ideas and experiences.

³ India did not receive any funding from the first round of funding (interview data UNAIDS Delhi).

2.3 Competing discourses in HIV/AIDS policy

2.3.1 Introduction to biomedical discourses of HIV/AIDS

Cultural critiques of biomedicine highlight the manner in which biomedicine structures accounts and understandings through a series of binary oppositions, for example health/illness, mind/body and doctor/patient. The root causes of illness are located within the body of the individual and diseases are described, causes identified and names assigned through a process of scientific research. (Persson et al 2003, Fox 1998). This process allows for little if any consideration of the social context within which health (or the absence of it) is experienced. Nor does it engage with the subjective experience of individuals:

Biomedicine presents a view of the 'body' as abstracted from particular social and historical contexts and lived experience, and is premised upon the power of experts to define problems. Biomedical knowledge and practice involves the separation of mind from body, culture from nature, society from biology and subject from object (Peterson & Waddell 1998:7).

This has implications for how problems relating to ill health are understood and consequently managed. Persson et al (2003) note that the individuals' experience of 'ill health' may be complex and socially negotiated, and as such offer very different perspectives to those emerging from within biomedicine. There is a clear analytic distinction between the clinical representation of illness and the lived experience of illness. Within biomedicine there is a clear order, or hierarchy, of who can speak and what types of knowledge are privileged with biomedical interpretations take precedence over lay interpretations of health and illness. Furthermore this dominant position is premised upon biomedicine's claim for truth and objectivity (Peterson & Waddell 1998). Against this background the following section explores the intersection of a number of biomedical discourses, arising from within the sub-

disciplines of virology, clinical medicine and epidemiology, and the discourse of HIV/AIDS that arises from this engagement. The knowledge constituted through these discourses has been influential in furthering understandings of HIV/AIDS as a problem associated with specific designated groups.

2.3.2 Biomedical understandings of HIV

Above it was suggested above that biomedical discourses are culturally constituted. This can be seen in the manner in which 'biomedical facts' about HIV/AIDS have incorporated cultural and political understandings and beliefs within them. As such there has been a blurring of the line between biomedical accounts of HIV and its affects at the cellular level and social, political and cultural interpretations of risk and vulnerability at the individual and societal level (Waldby 1996).

This blurring of the line is embedded within discursive practices and the manner in which figurative language is employed in the production of texts. Biomedical texts have historically used military metaphors to describe the functioning of the immune system and the ways in which the body responds to disease. This is well described in relation to cancer (Sontag 1991). In HIV/AIDS, the language of invasion and ultimate defeat is commonly used to elucidate what is happening at the cellular level (Sontag 1991, Waldby 1996). However, importantly in this context, these texts fail adequately to separate the virus from the host. As these texts are re-written and re-interpreted both for and by, a lay audience (the media, policy makers, politicians and health education materials) the 'site of the battle', (to borrow the metaphor), shifts from the cell to the individual. Consequently, at the linguistic level, individuals are targeted not the virus (Golden 1994, Waldby 1996).

Epidemiology, in its turn, picks up this language of invasion and uses it to create a coherent narrative to 'explain' how, when and where HIV spreads from individual to individual. Thus the infected individual becomes the reference point for understanding the disease and ways of controlling its spread. Further,

Despite, or perhaps, because of biomedicine's assertion of its own innocence of historical and political meaning, it consistently absorbs, translates and rearticulates 'non-scientific' ideas - ideas about sexuality, about social order, about culture, in its technical discourse (Waldby 1996: 5).

Thus biomedical discourses have picked up on socially constructed categories of exclusion and stigmatisation and incorporated them into explanatory models of risk. This model is discussed in the following section.

2.4 Constructing risk and vulnerability

2.4.1 Risk Groups

The term 'risk group' was first used in connection with AIDS in 1983. The Centers for Disease Control in the USA described a risk group as a 'sub-population vulnerable to both contracting and transmitting AIDS' (Waldby 1996: 5). The risk groups identified were the so-called '4H's'; homosexuals, heroin addicts, haemophiliacs and Haitians (Weeks 1989). With respect to social constructions of the pandemic many of these early groups were already stigmatised and marginalized, and AIDS became synonymous with deviancy and a culture of blame (Wolffers 2000).

With the identification of HIV the focus shifted, theoretically at least, from groups to individual behaviours (Wolffers 2000). Whilst HIV could, at this juncture have been categorised as a blood born infection (like for example hepatitis), it was instead categorised as a sexually transmitted infection (Asthana & Oostvogels 2001).

Similarly, whilst evidence continued to emerge of HIV spreading amongst heterosexuals, it remained synonymous with gay men. Anal sex became the defining act that represented risk and bound up with this were perceived beliefs about deviancy (Patton 1993).

At the political level and via certain sections of the media, stigmatised groups were held to be to blame for having contracted the virus through 'deviant acts' such as anal sex, 'promiscuity' and drug use (Holden 2003). Correspondingly a new discursive category emerged to mirror this, namely 'innocent victims'. 'Innocent victims' contracted the virus through contaminated blood products or vertical transmission (Gwyn 1999). They were not to blame for carrying the virus, they had contracted it through 'no fault of their own', an assertion that at its heart places blame onto the members of other risk groups (Watney 1988, Golden 1994, Gwyn 1999). The major modes of transmission have been identified and it has become clear that, in many societies the general population- not only those with identified 'high risk behaviour'- is at significant risk of HIV infection (Cleland & Way 1994:1)

Such distinctions fed the growing stigma surrounding the virus and became a device for labelling those infected as deviant. A number of studies published in 1983 found HIV amongst heterosexuals in parts of Africa (Downing et al 1984, Bayley 1984). These proved conclusively that HIV was not the exclusive purview of gay men, something already clear from the earlier epidemiological profiles of infection. However, these findings linked heterosexual spread with the number of sexual partners a person had had (Piot et al 1988). As such, promiscuity and prostitution were seen as major contributory factors. This intersected with the notion of HIV as a disease of deviancy.

The identification of risk groups contributed to the stigma associated with HIV/AIDS. Furthermore it has been argued that the concept of risk groups has limited potential to actually explain the epidemic because it offers a single explanation for what is 'a complex social phenomenon...' (Seidel & Vidal; 1997:65-66 citing Zwi & Cabral; 1991). Cleland & Way writing in 1994 noted that:

The major modes of transmission have been identified and it has become clear that, in many societies the general population- not only those with identified 'high risk behaviour'- is at significant risk of HIV infection. (Cleland & Way 1994: 1)

Despite this, the concepts of risk groups and risk behaviours continued to be used through the 1990s to aid the development of epidemiological profiles of countries and as a basis for developing prevention and control strategies. The shift in terminology from risk group to individual risk behaviours was supposed to bring about an evolution in the approach to epidemiology and prevention efforts. In reality most policies continued to target a group with shared characteristics which operate 'in proxy' for specific behaviours (Delor & Hube 2000).

Consequently education around HIV was encoded for these two different audiences, mass education campaigns that aimed to provide reassurance to the 'general population' and targeted information for the ubiquitous risk groups.

With this division in place, a new set of messages began to emerge, pared down to 'You can't get AIDS' and 'You can get AIDS'. The problem now faced by the subject of education was not how do I avoid the virus but which of those 'You's am I? Am I a member of the public or am I a member of the community at risk?' In this context, public came rapidly to mean those not at risk, and community those 'at risk', thereby encoding a system of social differences which conflates deviancy and risk. (Patton 1990:13).

This encoding also provided a rationale for policies that in essence were discriminatory or breached human rights (Waldby 1996).

2.4.2 High Risk Situations.

Despite the constructions of risk described above, it was clear by the late 1980s that many parts of the developing world were experiencing rapidly evolving epidemics that could not be explained in biomedical and behavioural terms alone. In these resource poor settings, infection with HIV was bound up with poverty and inequality. As a result, two distinct patterns were emerging. In Australia, North America and Western Europe death rates were beginning to plateau and in some instances fall. With the introduction of Anti Retroviral Therapy, HIV needed no longer to be a 'death sentence' but a chronic manageable disease given appropriate support and access to treatment (Poku 2002, Shadlen 2007). Meanwhile in the developing world, HIV morbidity and mortality continued to climb. That this was clearly understood at the global level is shown by the theme of Twelfth World AIDS Conference 'Bridging the Gap'(Woolfers 2000).

Zwi and Cabral writing in 1991 proposed the use of a new term 'High Risk Situation', which would include social, economic and political factors that contributed to the risk of infection experienced by groups. Whilst these factors were inevitably context specific, certain conditions arising from them, such as homelessness, landlessness, unemployment, rapid urban settlement, migration, population relocation and poverty, would indicate that a population was vulnerable to infection. Highlighting the essentially political nature of identifying high risk situations they argued that:

As well as identifying more appropriate forms of health education, recognising high risk situations may also reveal the need for more fundamental change. stimulating development, creating income generating opportunities, and addressing global economic imbalances and Third World Debt. (Zwi & Cabral 1991: 1528).

Within this 'development' model of HIV/AIDS, vulnerability became a key concept. Like so many terms, however, it is widely used but ambiguously so (Delor & Hubert 2000). Barnett and Whiteside offer the following definition:

Vulnerability describes those features of a society, social or economic institution or process that makes it more or less likely that excessive morbidity and mortality associated with disease will have negative impacts. (Barnett & Whiteside 2002: 166).

These features will be context and time specific and they may include some of the following; lack of access to appropriate health care, gender inequalities that restrict opportunities for employment or prevent women from making choices about the nature of their sexual relationships, and unemployment and under employment which force people to leave their homes to look for work. An associated concept is that of susceptibility which refers to 'any set of factors determining the rate which the epidemic is propagated' (Barnett & Whiteside 2002: 85). The presence of high rates of undiagnosed sexually transmitted infections or malnutrition would fall into this category and they may be closely allied to the concept of vulnerability. What becomes clear from this is that programming focused exclusively on individual behaviour change is unlikely to be an adequate response to vulnerability and susceptibility emerging from a high risk situation.

Zwi and Cabral's work reflects a conceptual shift from risk groups and risk behaviours to risk environments. However as was noted above, with the earlier shift from risk groups to risk behaviours, this 'lexical update' contains a time lag and all three terms have continued in common usage (Seidel & Vidal 1997). Indeed, it could be argued that during the time frame of the study, strategies for prevention and control within the context of resource-poor setting used the language of risk situations, whilst continuing to offer interventions that were based upon biomedical and behavioural understandings of HIV/AIDS.

2.5 HIV/AIDS programming within resource poor settings.

2.5.1 Introduction

The preceding section looked at the manner in which, during the early years of the pandemic, biomedical understandings and accounts came to dominate understandings of the HIV/AIDS epidemic with respect to explaining who was most at risk of being infected and why. In response to this, and against a background of increasing rates of infection within some Less Developed Countries (LDCS), a development discourse emerged during the early 1990s. This challenged the explanatory capacity of dominant biomedical discourses. Instead it highlighted the need to identify high risk situations and to consider factors contributing to vulnerability and susceptibility within given populations rather than focusing exclusively on individuals and individual behaviour. Against this background, the licensing of Anti Retro-Viral Therapy (ART) created another developmental dimension to the global pandemic. With the advent of ART it became possible, in developed countries, to view HIV infection as a long-term chronic illness, whereas, it remained 'incurable' when reference was made to it in Less Developed Countries. In reality it is curable in neither context but is manageable in both provided that the appropriate biomedical technologies are made available to those who need them.

This tension between what was technically possible, as opposed to what was considered to be practicable in terms of economics and delivery, was clearly articulated in the policy documents and statements concerning the pandemic produced by key sections of the global public health community (World Bank 1999a). During the time-frame of this study despite the availability of biomedical technologies such as ART and treatment options for opportunistic infections, AIDS

was presented as incurable and fatal hence the slogan 'Prevention Is The Only Cure' (Piot 2001). This rejection of ART for developing countries was based primarily upon the expense of these new drugs, but it also reflected concerns about the complexities of prescribing and monitoring ART and the challenge of drug adherence. The globalization of HIV did not, at this juncture, extend to the globalization of treatment options. This position is clearly articulated by Gibney when discussing options for prevention and control within the context of resource poor settings:

...for the developing world, biomedical and behavioural interventions to prevent transmission of the virus remain the only hope for reducing the mortality, morbidity and social trauma associated with HIV infection. (Gibney 1999: 2).

This can be read as an example of neo-colonial development discourse that sets the terms of the debate by excluding certain options, in this case ART. Against this background, this section is concerned with the development of approaches to HIV/AIDS prevention and control as presented in global guidelines for best practice and their use within resource-poor settings. It will begin by looking at strategies for prevention and control drawing out the differences between an intervention based and programmatic responses and situate them within developing understandings of HIV/AIDS. It will then consider some of the limitations found in the theoretical models upon which behavioural approaches to prevention have been founded. The implications for human rights and care and support are considered in Section 2.6.

2.5.2 Prevention and control

2.5.2.1. Targeted Interventions - defining the term

Singhal & Rogers offer the following definition of an 'intervention': '...[it] refers to actions with a coherent objective to bring about behaviour change in order to produce identifiable outcomes' (Singhal & Rogers 2003: 39). Bonell & Imre (2001) suggest that behavioural interventions '...aim to alter behaviours that make individuals vulnerable to becoming infected or infecting others (Bonell & Imre 2001: 155). These interventions may be targeted towards groups or members of a particular group or they may be population based (Gibney 1999). Interventions may be based upon biomedical, behavioural or structural prevention strategies although in reality an intervention may incorporate a number of strategies. For example, an intervention with the aim of promoting condom use in female sex workers could include a biomedical component (the condom), behavioural strategies to bring about this behaviour change (peer education and outreach) and structural strategies to address contextual factors (strategies for empowerment).

Against this background, the targeted intervention approach can be understood as the delivery of one or more interventions, to a designated group, or member of a group, aimed at bringing about a change in behaviour and thus reducing the risk of HIV transmission. The composition of individual targeted interventions may vary according to context, the group being targeted, the ideology of those developing and delivering the service, and so forth. During the time frame of this study targeted interventions amongst high risk groups were the mainstay of prevention and control programmes in resource poor settings. It was at this juncture that NGOs were incorporated into prevention and control activities.

2.5.2.2 Overview of different prevention strategies

With no available vaccine, biomedical strategies are geared towards preventing transmission of the virus from one infected individual to another. A number of these, for example screening all donated blood and blood products, the use of universal precautions for prevention of occupational exposure within health care settings, and the provision of post exposure prophylaxis rely upon an institutional response. Similarly, the provision of ART to pregnant women in the later stages of pregnancy to prevent vertical transmission demands an integrated and co-ordinated response from care providers. Other biomedical approaches focus on the individual. These include the use of male and female condoms, male circumcision, the treatment of sexually transmitted infections and the provision of ART to prevent further re-infections. Despite ongoing research into topical microbicides these have not yet been shown to be successful (Padian et al 2008).

The evidence for how well these different technologies work is mixed and their assessment is a significant challenge (Gupta et al 2008). For example, the male condom has been reported as being as much as 95% effective in preventing HIV transmission (Padian et al 2008). However estimates of effectiveness vary widely and consistent use is a key factor in this because condom use is context specific, hence an individual may not use condoms consistently (Hearst & Chen 2004). The evidence to support the role played by STI treatment in preventing spread is also mixed. It has been suggested that this is a more effective intervention in the early stages of the epidemic before behaviour changes have taken place in a given population (Padian et al 2008). This gives some indication that even seemingly straightforward interventions need to be understood in relation to the context

(individual and societal) in which they are used, and draws the important link between biomedical and behavioural interventions.

Coates et al (2008) offer the following definition of a behavioural strategy:

We define behavioural strategies as those that attempt to delay onset of first intercourse, decrease the number of sexual partners, increase the number of sexual acts that are protected, provide counselling and testing for HIV, encourage adherence to biomedical strategies preventing HIV transmission, decrease sharing of needles and syringes and decrease substance use. Behavioural strategies to accomplish these goals can focus on individuals, couples, families, peer group or networks, institutions and entire communities. (Coates et al 2008: 670).

As this suggests, biomedical and behavioural strategies are better understood as mutually complementary, and in reality it can be extremely difficult to isolate individual interventions for evaluation. Hearst & Chen (2204), discussing the success of prevention efforts in Thailand and Uganda where condom use was heavily promoted, make the important observation that it was not condom use alone, but also partner reduction that contributed to their success. They advocate the integration of strategies likening this to integrated campaigns for road safety where multiple elements are promoted together rather than in competition one with another.

More recently, approaches to prevention have begun to incorporate understandings of structural factors contributing to risk or vulnerability - this can be at the policy or the programmatic level and corresponds to the development model. These structural interventions seek to tackle the root causes of risk and vulnerability. Structural factors can be physical, social, cultural, organizational, community, economic, legal or policy-related and they need to be seen as being part of an expanded and integrated response and not as instead of or separate to one (Gupta et al 2008). As

the list of possible factors suggests, this is a highly complex and potentially more political undertaking. Gupta et al note that:

...progress in incorporating structural approaches into HIV prevention have been limited because of a lack of conceptual and technical consensus...they are commonly viewed as long term initiatives more to do with developmental goals and strategies...(Gupta et al 2008: 764).

These structural approaches reflect the growing acceptance of development understandings of risk and vulnerability and of ongoing attempts to synthesise the two perspectives. Thus they indicate the recognition at the global level that an expanded and inclusive approach to prevention is needed and that the two broad trends in approach to HIV/AIDS prevention need not be mutually exclusive.

Notwithstanding the success of some of these interventions in particular contexts, globally, HIV infection rates continue to rise. It has been suggested that fewer than 10% of people at risk from contracting HIV globally have actually been reached (Merson et al 2008) hence the need to scale up and expand prevention efforts. Where success has been achieved it has been difficult to maintain (Coates et al 2008). The evidence suggests that an expanded and inclusive approach is needed to HIV prevention that can integrate behavioural, biomedical and structural strategies and do so in conjunction with treatment. This is called 'combination prevention' (Merson et al 2008, Coates et al 2008).

The concept of combination prevention is indicative of the fact that the approaches taken to prevention, and the frame-work within which they are conceptualised, has evolved over time. As such ongoing research into HIV/AIDS prevention and what works has shown that rather than delivering an intervention, or a limited range of interventions in isolation, prevention is more likely to be successful if a comprehensive range of interventions are provided as part of a programme. Lamprey

(2002) describes an effective HIV prevention programme as one that is comprehensive and incorporates within it prevention, care and treatment.

UNAIDS (2005) provides a conceptual framework for HIV prevention programmes highlighting that:

HIV prevention programmes must be comprehensive in scope using the full range of policy and programmatic interventions known to be effective... not implementing exclusively one or a few selected actions in isolation. (UNAIDS 2005: 17).

Within the context of HIV prevention UNAIDS distinguishes between policy actions and programmatic actions. Policy actions address societal factors that contribute to vulnerability to infection and also create the necessary supportive environment in which prevention programmes can be successfully implemented. So one aspect of essential policy action for governments is to 'promote programmes targeted at the HIV prevention needs of key affected groups and individuals' (UNAIDS 2005: 23). Programmatic actions directly address the risk of transmission of HIV. These include the prevention of the sexual transmission of HIV, the prevention of mother to child transmission, the prevention of transmission through injecting drug use, the promotion of access to voluntary testing and counselling and the integration of HIV prevention into AIDS treatment services (UNAIDS 2005: 32).

2.5.2.3 Strengths and limitations of HIV/AIDS prevention strategies

As was suggested above, the complexity of prevention strategies can make it difficult to evaluate their effectiveness. Furthermore, whilst there have been some success stories for example Thailand, Rwanda and Zimbabwe, global rates of infection continue to rise year on year (UNAIDS & WHO 2008). This has been linked to the lack of overall coverage of those at risk (Merson et al 2008), the

application of a limited range of interventions (Coates et al 2008), and more recently a focus upon treatment and ART provision over prevention. Notwithstanding these problems, there is also a body of opinion that suggests that the theoretical models upon which much prevention work is based fails to account for human behaviour and human agency (Evans & Lambert 2008, Thomas et al 2008).

Thomas et al (2008) suggest that core assumptions incorporated into biomedical approaches to HIV/AIDS prevention have an impact upon their effectiveness. First, they assume that people are 'rational' actors who will behave in a manner to reduce their risk of infection. However it is well recognised that awareness and behaviour change are not synonymous. Further they fail to engage with contextual factors that shape people's choices. Coates et al suggest that behavioural strategies have been of limited benefit because:

... the theories guiding most interventions are essentially cognitive and individualistic and assume people have the motivation and freedom to adopt protective action. These theories generally do not address the fact that, whether in sexual contact or injecting networks HIV transmission is a social event and many factors other than perceived threat, knowledge, self-efficacy, behavioural intentions and perceived social norms affect whether or not an individual is going to share needles or have sexual intercourse and whether then sexual intercourse will potentially involve transmission risk (Coates et al 2008: 676).

One such theoretical approach can be found in the Knowledge, Attitude, Belief and Practice model (KABP). The World Health Organization's Global Programme on AIDS first developed a prototype KABP survey tool, for use in the AIDS pandemic, in 1987. It takes the form of a questionnaire for use with a sample of a given population. Respondents answer questions about their knowledge of AIDS, their attitudes and beliefs about AIDS and their intended behaviour in the light of this knowledge (Joffe 1996). This information can then be used to plan interventions and monitor behaviour change over time.

The KABP paradigm is based upon two models found in social psychology. These are the Health Belief Model and the Theory of Reasoned Action (Joffe 1996). These models are grounded in the presumption that knowledge affects attitudes and that attitudes can in turn be used as a predictor of behaviour. Thus, in the case of HIV/AIDS, if people are informed of their risk and vulnerability and told how to reduce or eliminate these they will choose to do so (Joffe 1996). KABP studies and the prevention strategies based upon their results are thus grounded in the assumption that thoughts lead to actions. This is however debatable on both empirical and theoretical grounds. As Joffe notes, '...there is limited evidence that AIDS-related knowledge and attitudes shape AIDS related practices...' (Joffe 1996: 171).

The KABP paradigm and the studies derived from it fail to elucidate the contextual factors that contribute to situations of risk and vulnerability and the range (or limitation) of choices available to people. There has also been a failure to conceptualise human sexuality in these models or to understand that 'risk behaviours' are social interactions that have meanings for people above and beyond notions of risk and deviancy (Coates et al 2008). KABP studies place emphasis upon the frequency and type of sexual acts and rates of partner exchange and there is an over reliance on the explanatory capacity of this quantitative data (Boyce et al 2007). Theoretical approaches drawing upon other research traditions have been neglected. More nuanced understandings of pleasure, the desire to have children or the meanings that people attach to their sexuality are over looked. As Boyce et al highlight:

...behavioural quantification alone is analytically insufficient to conceive the cultural depth, individual richness, inter-personal complexity, social

diversity, and practical malleability of human sexual experience. (Boyce et al, 2007: 9).

The simple invective to use a condom highlights many of the underlying tensions within these behavioural approaches. First there is little understanding of how the willingness, desire or capacity to use a condom may be time and context specific- as evidenced by the work on high-risk situations. It fails to recognise that women (and men) may want to conceive a child (Patton 1993, Oppenheim 1994). Further, condom use has been associated with 'deviant' sex in policies and couples in a 'monogamous' relationship may be reluctant to use them.

2.6 Normalizing the pandemic

The issues discussed in the preceding section raise a number of challenges for policy makers. First, is the question of where to target efforts at raising awareness of HIV/AIDS, at members of the so-called high-risk groups or at the 'general public'? This question remains a contentious one globally (Kallings 2008). Second how can interventions raise awareness in a way that doesn't also heighten fear and panic but at the same time doesn't lead to complacency? Third how can the 'othering' of the pandemic, which has led to significant human rights abuses throughout the world be addressed and reversed?

The term 'normalizing the pandemic' has come into use in recent years (Decosas & Finlay 1993, Piot and Aggleton 1998, Rosenbrock et al 2000). This describes a process whereby as the pandemic becomes more visible the early responses of panic and discrimination against infected individuals decrease and families and communities come together to provide a supportive environment in which to care for those who are affected. There is an important caveat to this process of normalization however, one that has only been recognised in the past few years. Any sort of

'normalization' as envisaged above is predicated upon the availability of appropriate care and support for those affected and for all responses to HIV/AIDS to become embedded within a human rights framework that supports and protects those affected by the pandemic. This chapter will conclude by considering what this means in practice.

2.7 Care and Support

2.7.1 Introduction

The primary assertion made throughout this chapter has been that biomedical understandings of HIV/AIDS have set the terms by which the pandemic has been understood, despite efforts in recent years to be more responsive to structural factors that contribute to risk and vulnerability. Although there is clear evidence that biomedical and behavioural approaches do reduce HIV transmission, the challenges to sustained change, and the reversal of HIV/AIDS infection rates at the country level, remain daunting. As was noted above UNAIDS now advocates a programmatic approach to HIV/AIDS prevention which included responding to contextual factors influencing transmission and also incorporates care and support (UNAIDS 2005).

Against this background, this section is concerned with two interrelated problems associated with the HIV/AIDS pandemic both of which at the time of the study were seen as largely (although not entirely) the provenance of NGOs. The first is the problematic response to the need to provide care and support for those infected/affected by the virus. The second is how to maintain and promote the human rights of those implicated with spreading the virus, against a backdrop of wide spread stigma and discrimination.

Whilst much has been made of its global character, the HIV/AIDS pandemic is manifesting itself very differently in different contexts. Whilst biomedical discourses have dominated understandings of the pandemic within the context of resource poor settings, advances in the delivery of biomedical technologies (for example ART) have not been translated into action with respect to care and support. This is in many ways surprising given that the provision of ART has become a core component of policy and programming since the UNGASS declaration of 2001 with the 'roll out' of ART and the provision of treatment globally a target for the Millennium Development Goals (Shadlen 2007)⁴. Whilst care and support for those in resource poor settings are no longer off the agenda, as they were during the time frame of this study, movement towards the goals set for the delivery of ART has been slow (Kallings 2008).

Notwithstanding this, it is now well understood that a comprehensive prevention programme includes the provision of ART and other approaches to care and support (Lampthey 2002). Leaving human rights aside it is now recognised that the provision of HIV care is frequently the access point to HIV testing (Gilks 2001). Therefore if care and support are available there should be an increase in the take up of testing. This in turn will lead to more people undergoing counselling aimed at prevention (Kitahata et al 2002). This is beginning to be translated into action (Gupta & Pillay 2007) and this change is a welcome one and reflects a number of coalescing forces.

First, one of the lessons from twenty years of programming for HIV/AIDS

⁴ At the UN General Assembly Special Session on AIDS 2001 (United Nations 2001) targets were agreed by all of the then 189 countries in the world. These included the reduction of HIV prevalence amongst people aged 15-24 by 25% globally by 2010, and a 50% reduction in infants infected by HIV. These targets are to be achieved, especially the latter, by increasing access to ART (Kallings 2008: 236). In 2003 UNAIDS and the WHO launched its '3 by 5' initiative for 3 million people to have access to ART by 2005. Although this was only partially met (1.5 million), it signalled a sea change in attitudes. Significantly at the G8 Summit in Gleneagles in 2005 a goal of universal access to ART by 2010 was made (Shadlen 2007).

prevention has clearly been that the absence of treatment for those affected is a stumbling block to successful prevention activities (Piot 2001, Lamptey 2001). Second, biomedical and pharmaceutical advances have led to the availability of preparations containing a combination of drugs, making them easier to take (Heywood 2004). Third the increasing availability of generic ART and a corresponding reduction in price has also made ART more accessible in resource poor settings (Shadlan 2007).

Fourth, the campaigning and global alliances of activists, NGOs and civil society organizations demanding the provision of ART as a basic human right have had a significant impact. The success of the South African based Treatment Action Campaign (TAC) in taking on multi-national pharmaceutical companies, the global outcry at the restructuring of the World Trade Organization and the introduction of patents on drugs under the TRIPS agreement, all provide examples of globalization acting as a force for the marginalized and less powerful members of a global society (Halmsaw & Hankin 2004). Fifth, the movement towards global access to ART also needs to be understood as arising from the increasing recognition that HIV presents a threat to global security (Merson et al 2008).

2.7.2 Care and Support. What are the issues?

The issues around care and support are undeniably complex and involve more than the availability of cheap generic antiretroviral drugs. There are many difficulties in providing ART in any context. These are well documented and include the supply, storage and correct prescribing of ART, the management of drug toxicity, ensuring adherence with regimes to prevent resistance and deciding when to change therapies when a regime is failing in the absence of laboratory testing facilities (Kitahata; 2002, Shadlan 2007). Drug resistance is a significant problem and

increasing numbers of people are presenting with resistance to first-line drugs (Mugenyi 2004, Gupta & Pillay 2007). The WHO has developed treatment guidelines and standardised antiretroviral drug regimes to help with these problems (Kitahata 2002, Gupta & Pillay 2007). However, the provision of ART is not in and of itself enough.

What is really needed is care across a continuum (Gilks et al 1998). This should define the services to be delivered at each level and strategies for appropriate delegation. It is this that will save lives and offer hope to those affected, hence reducing stigma, discrimination and isolation. The issue of providing care across a continuum is again a largely neglected area. This situation is complicated by a lack of available information about the relative burden of HIV disease in resource-poor settings. Gilks highlights the implications of this when he writes that:

...without knowing how much HIV/AIDS disease is presenting where and at what stage of disease progression it is impossible to adequately describe the care burden of any community. (Gilks 2001: 176).

Nor has there been sufficient work on providing appropriate care to communities that have little if any access to formal health services. The concept of community-based care and support is poorly articulated. It may amount to people suffering from treatable HIV related infections being left to die in extreme isolation, in part because there is little help available or because poorly trained health workers are unable to identify opportunistic infections that could respond to treatment. As Kallings succinctly puts it:

In developing countries, not even analgesics may be available, let alone antiretroviral treatment, and HIV infected people are dying with terrible suffering. (Kallings 2008: 224).

Nor have the goals set for access to ART produced particularly encouraging results. A 2007 review of the progress made towards achieving the goals set by UNGASS

found that only 8% of children in low and middle-income countries who need ART have access to it and that only 11% of pregnant women who were HIV positive were receiving ART (Kallings 2008: 236).

Into this vacuum NGOs such as The AIDS Support Organization (TASO) in Kampala, Uganda and the Y.R. Gaitonde Centre for AIDS Research and Education (YRG Care) in Chennai, India are developing a number of different approaches to care and support. However, NGOs are faced with the problem of being small-scale, suffering from inadequate funding and a lack of trained personnel. A recent study looking at NGOs involved in providing home based care in Zimbabwe found that the projects involved in the study needed support from the government to function successfully (Nsutebu et al 2001). As such there is a real need for care and support for those infected with HIV in resource poor settings to be integrated into mainstream services.

2.8 Concluding comments

This chapter has examined the development of a global response to HIV/AIDS with a particular focus upon resource-poor settings. In doing so it has identified a number of roles for NGOs in the implementation of policies for prevention and control of HIV. Biomedicine has been the dominant voice in explaining the pandemic and the prevailing policy responses reflect this. As such there has been a focus upon identifying risk groups and developing appropriate targeted interventions. These interventions are primarily concerned with bringing about behaviour change and the evidence regarding their success is mixed (Padian et al 2008, Coates et al 2008). However contextual factors are now understood to contribute to high risk situations that make communities and the individuals within them vulnerable to infection,

therefore biomedical and behavioural approaches to prevention are unlikely to be successful on their own. Instead the structural, economic and political factors contributing to these high-risk situations need to be addressed. This is reflected in global guidelines that have fore-grounded the need for prevention strategies to encompass biomedical, behavioural and structural factors contributing to risk and vulnerability (UNAIDS 2005).

Against this background a significant role had been created for NGOs, during the time frame for this study, in relation to HIV/AIDS within the context of resource poor settings. First it was anticipated that they would be actively involved in the design and implementation of targeted interventions. This role was premised upon the assumption that they will be able to access those groups within any given community that were most at risk of contracting HIV and to work with them to bring about behaviour change. Second, it was anticipated that, in their role as community activists, they would be able to promote and support a human rights based approach to the pandemic countering the stigma and discrimination that had accompanied it. Third, it was expected that NGOs would be able to provide a safety net for those infected with HIV who were unable to access public or private healthcare services. It was envisaged that they would be instrumental in contributing to the continuum of care, particularly with respect to home and community-based care and support. Against this background the next chapter will discuss the aims of the research. It will provide a detailed explanation of the methodology chosen and the research design and methods arising from this.

Chapter Three

Methodology and Methods

3.1 Introduction

The purpose of this research is to explore the language and discourses of HIV and AIDS in India circulating at different levels of the policy process, from the mid 1980's until 2001, with a particular focus upon Non-Governmental Organizations based in Kolkata, West Bengal (see section 3.3.1 for a detailed description of the aims of the research and research questions). This chapter provides a discussion of the theoretical approach taken to the research and how this was implicated in the overall research design. As such this chapter will be divided into three sections. Section 3.2 will discuss the analytic framework employed within the study and provide an exploration of the epistemology underpinning the study. Section 3.3 will describe the methodology, research design and methods used. Having provided this theoretical background, the third part of the chapter, section 3.4 will discuss the actual research process including fieldwork and data collection, data analysis and writing up.

3.2 The Analytic Framework

3.2.1 Introduction

The analytic framework employed in this study is concerned with an analysis of international, national, state and NGO perspectives, and the discourses and discursive positions underpinning different responses. This framework and the rationale for adopting this approach are discussed below. Section 3.2.2 explores Walt and Gilson's (1994) model for analysis of the health policy process. Section

3.2.3 explores the epistemology informing the discursive approach taken to the research.

There are many different approaches that can be taken to health policy analysis. These often draw upon linear models of the policy process to explain the different stages of a policy from agenda setting to implementation and are, as a rule, underpinned by realist assumptions (Hogwood and Gunn 1984, Lee and Mills 1982). However, as Ham points out, the health policy process is 'a highly political process in which power and entrenched interests are the main driving forces' (Ham 1991: 65). Shore and Wright (1997: 8) working from within anthropology provide a useful means of conceptualising policy when they suggest that policies may 'be analysed as examples of analytic keys to understand an entire cultural system and its underlying elements...'. They argue that focusing on policy provides a means of studying the local impact of processes of globalization. Viewed in this way, policy is seen as an important organizing concept in western and international governance. Despite its inherently politicised function, policy is still often analysed as if it were politically and ideologically neutral (Shore and Wright 1997).

3.2.2 The work of Walt & Gilson

Against this background, Walt and Gilson (1994) suggest that historically, health policy has focused on the content of policies rather than the policy-process, that is on the technical features of policy rather than the processes involved in putting policies into action. A consequence of this, they argue, has been the ineffectual implementation of policies and a failure to achieve expected outcomes. Therefore they argue for the need to look not only at the content of policies but also the context, actors (as individuals and as members of groups) and processes involved (Walt and Gilson 1994). This, they argue, is particularly important in the context of

a policy environment that is both more uncertain and more conflictual and which incorporates new actors both as individuals and as organizations. As such, the values and group interests underpinning changing health policy need to be recognised. The analytic framework proposed by Walt and Gilson can be used both prospectively in the planning phase and retrospectively as in this study. Walt and Gilson emphasise the important role that actors in the policy process play both by influencing the values within the policy and the choice of policies. The context within which policies are designed and implemented (political, historical, socio-cultural and economic) also have a significant effect upon the policy process and therefore needs to be recognised and understood.

Walt (1994) expands on this, arguing that the implementation of policies should not be understood as being part of a linear policy process but rather as a complex interactive process, that can incorporate both 'bottom up, and 'top down' elements⁵. Whilst policies may be designed at the international or national levels, the actors involved in implementing policies may significantly affect the manner in which the policy is implemented and be instrumental in bringing about change. Interest groups and civil society organizations (including NGOs) can also bring different perspectives and values to bear. Walt proposes three layers for analysis, international, national and sub-national, exploring the processes and actors involved at each stage and asking how policies have been formulated, implemented and evaluated. Walt (1994) encapsulates this when she notes that:

...health policy is best understood by looking at both processes and power, which means exploring the role of the state, nationally and internationally, the actors within it, the external forces influencing it and

⁵ A top-down model assumes that policy formation takes place at the national or international level whereas a bottom-up model credits implementers with a significant role in policy formation and the capacity to feed back up to the national/international levels (Walt, 1994).

the mechanisms within the political system for participation in policy making. (Walt 1994:5).

In order to do this it is important to have some means of engaging with both the *processes* involved in the design and implementation of policy and the concept of *power*. The following section will discuss how power is theorised in this study and provides a rationale for focusing on the discourses and discursive positions underpinning the different perspectives. Section 3.3.5 discusses in detail how the data was analysed and talks about the policy process.

3.2.3 Introduction to Epistemology

This section will situate the research theoretically and state what claims are being made about the status of knowledge within the study; that is to explore the epistemology and ontology informing the choice of methodology. It was noted that the topic selected was concerned with the language and discourses of HIV/AIDS. As such, the approach taken to the research itself is informed by the linguistic turn within the social sciences. It engages with post-structuralism and discourse theory and the practice of discourse analysis.

The use of discourse analysis represents a significant break with a positivist/post-positivist approach to social research. However, the term 'discourse' can be difficult to define and its deployment can vary across disciplinary boundaries both with respect to methodology and methods. This has implications for health policy analysis which is by nature an inter-disciplinary field of study. Wetherell (2001) suggests that there are six more or less distinct traditions in discourse research. For these reasons it is important to state explicitly, at the outset how the terms are being used and which authors and bodies of literature are being drawn upon to provide the theoretical framework.

3.2.4 Epistemology: central themes in post-structuralism

This section will identify three key themes within post-structuralism that delineate the manner in which language and discourse are understood to operate and will identify the implications of these for how a piece of discourse analytic research can be conducted. Specific reference will be made to the work of Michel Foucault throughout. It is useful to begin with a definition of 'discourse' although this is not necessarily an easy undertaking as perspectives and thus definitions vary. Taylor states that the term 'discourse' is 'wide ranging and slippery' (Taylor 2001a: 8) although a useful definition is offered by Wetherell: 'discourse is talk, language in use and human meaning-making activities' (Wetherell 2001: 27).

Against this background, the first theme relates to the nature of language and the manner in which it represents the world. The positivist paradigm embraces a realist world-view. Thus, language is seen to represent the world in a straightforward and unproblematic way. The post-structural position is entirely different. Language creates the subjects that it describes, it does not simply reflect them (Wetherell 2001: 16). Closely related to this is the idea that discourses are time and context specific and rely upon inter-subjectivity to create meaning and understanding. Discourses are not static, rather they are fluid and can be opportunistic, drawing on existing discourses and engaging with commonly held beliefs and normative ideas (Carabine 2001). Thus, there can be a slippage in meaning from one context to another.

The second theme concerns the relationship between power, knowledge and discourse. This section will draw upon Foucault's idea of Power/Knowledge (Foucault 1978; Gordon 1980). For Foucault, discourse (rather than language) was the object of his study and groups of statements were the starting point for his work (Hall 2001). Discourses produce the objects of which they speak, for example

sexuality or madness (Carabine 2001). These discourses also provide a framework, not just for talking about these objects, but for how to manage them and a corresponding justification for the exercise of power in relation to their regulation and control (Bryman 2008).

Importantly, this idea about the exercise of power in Foucault's work has a materiality in that discourses are seen as having effects (Carabine 2001). For Foucault, power and knowledge are inextricably intertwined and knowledge of any kind is constituted in power relations. Power is not something exercised from the top down in some sort of linear process. Rather Foucault conceived of it as being diffuse across many sites, for example through religion, science and medicine. Further it operates throughout society at all levels both in the public sphere and the private sphere (for example the family and sexuality) (Hall 2001). This is reflected in the idea that discourses are rule-bound. Rules govern who can speak and from what perspective, what can or cannot be said and what form this takes (Aviles 2001). Discourses can also be said to make truth claims and in so doing define norms at any given moment in time. The third theme is the end of the 'grand narrative' which offers a linear, inclusive and realist account of the world. If knowledge is time and context specific and meaning is fragmented and constantly in state of flux then there can be no single version or account of the social world (Lyotard 1986, Twigg 2002).

These three themes have implications for the status of research emerging from within this theoretical domain. First, they undermine claims for generalizability by focusing on the contextual and embedded nature of knowledge. Whilst positivist research is evaluated using the criteria of validity and reliability, the evaluation of discourse analytic research is closely linked to the manner in which reflexivity is understood and incorporated into the study. Therefore this is discussed next.

3.2.5 Reflexivity: Introducing The Concept

Reflexivity is a term that is widely used within the social sciences but it has a number of different meanings and the manner in which it is used can vary considerably both within and across disciplines (Bryman, 2008). Gough suggests that 'at the very least, reflexivity means applying a critical perspective to one's own knowledge claims' (Gough, 2003:23). As such, the researcher needs to be understood as being 'part and parcel of the setting, context and culture he or she is trying to understand or represent' (Altheide and Johnson, 1994: 486). Furthermore, a commitment to reflexivity within the research process necessitates that the researcher be sensitive to the cultural, political and social context within which the research is situated (Bryman 2008).

Both Lynch (2000) and Gough (2003) highlight the contested nature of the concept. They suggest that 'reflexivities' might be a more accurate term, signalling 'current plurality, flexibility and conflict' (Gough 2003: 23). Correspondingly there is great diversity in how reflexivity is incorporated into research in terms of activities and objectives. Gough argues that:

A broad distinction can be made between *realist* uses of reflexivity, wherein researcher confession is deployed to reinforce the 'accuracy' or 'authenticity' of analysis, and post modern or *relativist* form of reflexivity, which tend towards disrupting narrative coherence and advertise analysis as constructed. ...[stress in original] (Gough, 2003: 26-32).

This study was informed by the latter of these two perspectives. From a post-structural standpoint, the knowledge arising from a piece of social research can be conceptualised as being co-created through the interaction of researcher and participants within particular contexts and it is therefore time and context specific. Finlay sets out the implications of this for a piece of social research when he writes

that 'meanings are negotiated within particular social contexts so that another researcher will unfold a different story' (Finlay, 2002a: 531). The choice of the word 'story' is important here because it draws attention to the essentially constructed nature of research texts. The researcher makes herself/himself visible within the research text rather than writing herself/himself out of it (Gough, 2003). Reflexivity can be seen to encompass both self-awareness on the part of the researcher and the active (re)presentation of the researcher (Brnman 2008).

Following on from this it is important to recognise that, in discourse analysis, reflexivity is implicated throughout the whole research process. This should ideally begin with reflection upon the research topic and questions and continue throughout data collection, analysis and writing up (Finlay and Gough, 2003). Finlay and Gough note that social research situations involve negotiation between researcher and participants, the latter of whom may have very different expectations and understandings of the research. These evolving relationships and their dynamic, inter-subjective nature need to be viewed reflexively as they contribute to understandings and meanings. The researcher should '*include such reflections as data in their own right ...*' (Finlay and Gough 2003: 103) [Stress added].

There needs to be continual evaluation by the researcher of her/his subjective responses and the inter-subjective dynamics between the researcher and research participants. The research process itself should also be evaluated with respect to the choices made. Finlay (2000: 531) describes this as 'explicit, self aware meta-analysis of the research process' (Finlay, 2000: 531). Being reflexive in this way can contribute to the overall evaluation of the study. As noted in section 3.2.6, embedded evaluation can help enhance the integrity and trustworthiness of

qualitative research. However, it also needs to be noted that, by the very nature of its subjectivity, reflexive analysis can be contested (Finlay 2002).

3.2.5.1 Implications for the researcher

What does a commitment to reflexivity in the research process entail for the researcher? I will begin by considering status characteristics and positionality, then explore the issue of conflicting identities when a researcher also has a professional identity. I will discuss this material in relation to my own subjectivity prior to entering the field and during the early stages when the parameters of the study were being established. I will return to them throughout the text and return to it again in chapter 8 when I review and reflect upon the study. It is also important to remember that reflexivity as a research undertaking is never complete in discourse analytic research because 'knowledge is constantly emerging and being constructed' (Ballinger, 2003: 67).

Bailey (1996) suggests that status characteristics of both researcher and participants such as gender, race, ethnicity, social class, sexual orientation, and age will all influence the research process both with respect to how a researcher presents himself/herself and with respect to how they are perceived by participants, gatekeepers and other individuals involved in the research. Furthermore, participants may present themselves according to how they perceive these status characteristics. In addition to these an individual's history, personality and belief systems will have a role to play in what the researcher considers as important and noteworthy. The subjective understanding of the researcher may change over time as relationships develop (or deteriorate) and perceptions and understandings change.

Power is clearly implicated in this and the researcher needs to understand and manage the imbalance of power between the researcher and research participants (Finlay 2004). Positionality is a useful concept here. It engages with the idea of power as something fluid and dynamic and where identity is both negotiated and shifting depending on time and place. Chako (2004) identifies positionality as an important concept in formulating, conducting and reporting field research and one that may help keep the researcher focused on the interplay of power relations in the production of knowledge. She describes it thus:

In keeping with the viewpoints of feminist theory, “positionality refers to aspects of identity in terms of race, class, gender, caste, sexuality and other attributes that are markers of *relational* positions in society, rather than intrinsic qualities. Unequal power relations are implicit within positionality. (Chako 2004:52)

Chako goes on to reflect upon her own experiences when conducting field research. She notes that this necessitated a re-assessment of her life and that this ‘self-reflexive contemplation’ helped her in turn to understand and negotiate her status and identity in relation to the study participants and study sites and to reflect upon her own prejudices (Chako, 2004: 55). She also identifies that there may be occasions where a researcher is caught between different identities for example in the transition between ‘home’ and ‘the field’ or between a public or private identity. The researcher needs to be aware of these shifting positions and negotiated identities and find means to cope with the feelings of emotional displacement that accompany the physical displacement.

3.2.5.2 The Professional/Researcher divide

The previous section considered ways in which a researcher’s status characteristics and positionality might be implicated within the research process. It was noted that the relationships between the researcher and research participants might be grounded

in unequal power relationships and that adopting a reflexive stance can help to understand them better. This section is also concerned with the identity of the researcher. It explores the implications of the researcher having a dual identity, namely being both a researcher and a professional, for researcher subjectivity. This is something that happens frequently in research around health, social care and health policy. Professional knowledge can be of considerable benefit because having identity as an insider allows access to data that may not be accessed by the outsider. (Arber 2006: 156). However, it may also present certain difficulties. It is an issue of particular relevance to this study because I came to the research as a nurse with a background in HIV/AIDS care - thus I had a dual identity as nurse and as researcher. This section will consider the theoretical difficulties associated with this 'professional/researcher' divide. My own subjectivity as nurse and researcher is discussed more fully in the following section. This is something that I return to at points throughout the text and again in chapter 8 when I review the study methodology in the light of the research experience.

First, it is important that the researcher recognise that he/she is also within discourse and as such needs to interrogate his/her own beliefs, feelings and taken for granted assumptions in the same way that he/she would do those of study participants (Arber, 2006). If not, they risk the danger of losing their reflexivity. Harper, a psychotherapist and researcher, describes some of the difficulties he experienced with this dual identity, particularly when some participants were referred to him as clients and clearly understood him to be 'linguistically, relationally and emotionally' part of the psychiatric culture (Harper, 2003:84). He describes himself as experiencing this dualism between discourse analyst and psychotherapist as being like a tight rope-walker. He identifies the problem of being embedded within the

culture and therefore finding it difficult to identify taken for granted assumptions. For example on occasion he found that accounts from service users seemed to be accurate descriptions of 'reality' because they tallied with his own views. Harper's response to this was to include himself in the analysis and to explore his own knowledge rather than taking it for granted.

Finlay (2004), an occupational therapist, conducting research on the life worlds of occupational therapists experienced a similar set of problems concerning his own position within the research as he observes:

Early in the research, I needed to work to unravel instances in which my participants and I shared understandings and ones in which we diverged. I had to guard against assuming that we shared the same language and saw the job in the same way; if I failed to do so I might have missed the point that there were differences (Finlay, 2004:537).

Arber, a nurse, with a background in oncology, identifies the way in which her familiarity with the specialised language and culture of the medical world and her sense of being 'at home' within it, presented a particular risk of her taking for granted aspects of this setting rather than holding them up to scrutiny (Arber, 2006).

Another challenge faces the researcher who may select or be assigned different research identities or responsibilities within and across different contexts. This professional/ researcher divide has implications for the choices that researchers make throughout the research process and in relation to how they manage their own emotions and sense of self. Ballinger (2003) cites the example of not wanting to present herself to elderly participants who had fallen in a situation where her 'knowledge' was privileged over their lived experience, as such this would run the risk of reproducing unequal relationships. This influenced how she dressed, the time she spent with respondents as opposed to staff and how she presented herself as a

researcher or post graduate student and not health care professional (Ballinger, 2003: 75).

Arber (2006) researching into the experience of pain within a hospice setting also considers the implications of this professional/ researcher divide for her research and the importance of reflexivity for managing the difficult feelings that this tension between nurse and researcher provoked. She reflects upon identity, not as being fixed but malleable noting that her role and her identity were constantly defined and re-defined within the context of the study and that expectations of her changed and her own perception of her role also had a liminal quality. This was particularly the case when observing the distress of patients or relatives in situations where as a nurse she would have been actively involved in helping individuals to manage this distress, but as a researcher was observing. Her observation was that on occasion study participants were also unclear about the boundaries of her role and would attempt to 'convert' her – that is to engage with her more actively as an experienced nurse. This she describes as a seductive option because it allows the researcher to be 'at home' in the practitioner role and thus calls for a degree of reflexivity and self-management to keep on her footing as researcher.

3.2.5.3 Constructing a narrative of self

The first submitted draft of this thesis contained little information about myself other than a brief account of the employment and educational experiences that underlay my choice of research topic. I went so far as to say that I had not 'explicitly stated how status characteristics (either my own or those of respondents) may have influenced the research process...'. I included nothing that I would have considered to be 'personal information' and steered clear of talking about my own lived experience of the research and the unfolding of relationships within the research

setting. This in part reflects my deep discomfort when faced with the prospect of writing about myself. This has not lessened over time. However looking back at this now, it seems very obvious that this constituted an essential part of the thesis and my failure to incorporate myself into the text was, I now believe, part of a deeper uncertainty about myself and ownership of the research. That I chose not to include this information is perhaps more surprising because the very nature of who I was and my subjective experience of living and carrying out research in Kolkata was a source of ongoing probing, discussion and reflection both at the time and subsequently.

Whilst in Calcutta⁶, I shared a flat with a fellow research student. We talked at length about our identity, relationships and how we positioned ourselves in relation to our lives in the UK and our roles as research students in Calcutta and how these impacted upon our inter-subjective understandings of the 'knowledge' that we were gathering to use for our respective studies. Whilst these conversations were inevitably personal and highly context dependent, a recurring theme for me was how I understood myself as a working class woman and the journey that I had taken (both literally and philosophically) in order to be in Calcutta doing my research.

That I loved my life in Calcutta and love the city itself still, perhaps goes without saying. However, this experience was continually cross cut with anxieties about being 'good enough', about doing the research 'well enough', about my abandoned nursing career which would have enabled me to 'do something useful'. At least some of this anxiety was class-based (although it makes me uncomfortable to admit this in this context) and it made me sensitive to the manner in which life and

⁶ I choose to speak of Calcutta here, rather than Kolkata, because that is the name that the city had when I first lived there, and the lexical update, whilst clearly necessary for accuracy does not best reflect my relationship with the city.

opportunity for so many people that I met was divided along class and caste lines. Whilst I would not claim ever to understand the lived reality of this for the people I met during my research, I did try to be sensitive and respectful wherever I went and to whomever I spoke - even if the cues from others were that this was not necessary, as was occasionally the case when a sex worker or truck driver was present. I always felt more comfortable away from the NGO offices preferring to be 'in the field' visiting small projects with outreach workers.

This intersected with my awareness that I, and my research, could be conceived of as part of a post-colonial discourse - one that I wished to try to understand - not replicate. As such, I was aware of the danger of constructing a narrative of the 'other' which foregrounded disease and reproduced essentialist accounts of Indian characteristics, qualities and sexual mores. I had seen quite a lot of this when working in Calcutta with other Western volunteers ⁷. I was particularly uncomfortable at the thought of being perceived to be a voyeur - as such complicit in objectifying the people who used the projects. I was also at pains not to act as if I felt I had a sense of entitlement, an unquestionable right to visit projects, to ask questions, to take people's time.

This, I believe, intersected with my complicated feelings about my nursing background. I was particularly struck by the fact that a visit to Mother Teresa's House of the Dying had become part of the 'Calcutta experience' for some Westerners and I was asked on several occasions if I had been. One view, often stated, was that it was a 'terrible place' and that I should see it for myself. Another, more measured perspective was that I might be able to make myself useful there. I never did go - it felt wrong. It felt reprehensible. But it made me aware that there

⁷ See Hutynk's book *The Rumour of Calcutta, Tourism, Charity and the Poverty of Representations* for an anthropological perspective on the volunteer culture in Kolkata.

were Western tourists who would confidently stroll into an Calcutta hospital 'just to see how bad it was' as one tourist told me. I am sure that this was in part due to my sense of professionalism as a nurse. I remember wondering at the time what we would have done, when I was working on an AIDS unit in London in the early 1990s, if tourists to London had wandered in for a look around to see 'how bad' things really were. I did not want to be implicated in this type of behaviour. My dual identity as nurse/researcher also had an impact upon the manner in which this research was conceived and carried out. This was a difficult issue for me throughout the study and one that re-occurred at different points. This is discussed in detail pages 114-115 in this chapter. I also return to it in chapter 8.

Further, there were the inevitable gender issues. Whilst I lived in India I continued to have a home in Oxford with my partner of many years. My relationship was a source of much interest to Indian friends, several of whom stated clearly that they could not understand why I did not go home and have a baby whilst there was still the time and opportunity. Over time I came to understand that what I took for a commonplace and uncontroversial lifestyle really did provoke surprise or even shock in some of the people that I was meeting. At the start of my research I had not really understood in any meaningful way the extent to which motherhood in particular, and notions of 'respectable femininity' in general, demarcated what was constructed as acceptable or unacceptable behaviour for women.

Two examples of this clearly spring to mind. The first highlighted for me the manner in which the freedom to move throughout the city, something that I took for granted was not shared by many of the women that I met. Many of the spaces that I visited were symbolically constructed as out of bounds for women if they wished to be perceived as 'respectable'. Early on in my study when I was flat hunting a

woman showing me a flat told me that, when I had told her that I had formerly lived on Sudder Street, she almost put the phone down. She said she did not even know of anybody who had ever been there, because it was a notorious red light district. However, I had come with good references and therefore she had decided to take a chance on me. As I noted in my diary she said 'You are a good girl, really do not tell people that you have gone to that place'⁸.

The second comment was from a woman that I met in a counselling workshop. She was very upset because her parents had placed a matrimonial advertisement for her in the paper and she was asking me about life in Britain for a single woman. When I told her that I lived with my boyfriend she told me how brave she thought I was and asked me what my parents thought of me being promiscuous⁹. This question has stayed with me because it encapsulates both the commonality and the difference that I found in many of my conversations and relationships whilst in India. Whilst my life choices were clearly very different to this woman's and my parents would never have classed my behaviour as promiscuous they strongly disapproved of it and do so on moral and religious grounds.

Given these interactions I felt that it was prudent to pick and choose with whom I discussed personal details and perhaps to err on the side of caution. However, there were circumstances when to have not reciprocated in an exchange of this kind would, I believe, have been both disrespectful and ungracious. It was during these kinds of exchanges that points of understanding and commonality or difference and misunderstanding could be teased out. Also it was at times like those detailed above

⁸This is the first destination for many foreigners visiting Calcutta who are travelling on a budget. I was not aware initially that it was neighbouring onto a red light district because it can be very difficult to 'read' the different lives within a given locale as an outsider. I only realised about this other side to Sudder Street and its environs when I read a reference to a 'Free School Street whore' in a novel by Amitav Ghosh. Free School Street traverses the top of Sudder Street.

⁹The word promiscuous and its meanings are discussed in chapter 4

that I was most aware of my gaze being returned and of being scrutinized myself. This helped to refocus me on the inter-subjective nature of all of these encounters. Throughout this time in India I wrote a reflexive diary and field-work notes which I returned to frequently whilst analysing the data and writing up and found them surprisingly evocative of the experience and the evolution of my own thinking about certain issues and experiences.

Finally, it is important to recognise that whilst I often felt that I had very little power in the research process, the reality was that people generally were very helpful and facilitated my research with little question of my entitlement. This may have been because of perceptions about my social status. I was very aware that by living on Southern Avenue I was living, for the first time in my life, somewhere highly desirable and that this conferred a certain status upon me. Certainly it helped that the director of the West Bengal Sexual Health Project, a DFID funded project, was supportive of my research and facilitated introductions for me. This was probably doubly useful in some instances because the WBSHP was funding several of the projects that I visited. It was also a high status organization because of its links to DFID. Of course for some people this may have had the opposite effect - linking me indelibly with the old elite colonial order, or making them feel unwilling or unable to say certain things for fear of compromising their relationship with their source of funding. This again highlights the possibility of reading this research as a post-colonial encounter.

3.2.5.4 Strategies for reflexive practice

Payne and Payne argue that reflexivity is about maintaining high standards within the research process because good research depends upon the decision-making capacity and the judgement of the researcher. They stress the importance of the researcher recording observations and importantly their feelings about those observations. This process can alert the researcher to feelings that may affect the process of data collection and analysis and can help to keep the experience alive during data analysis and writing up. One way of facilitating this reflexivity is by keeping a personal research diary (Payne and Payne, 2004).

This diary is a place where the chronological sequence of events, the evolution of the study, and theoretical perspectives and understandings can be recorded. Importantly, by keeping a research diary the researcher is also able to document feelings, emotions, and thoughts alongside events and processes as they unfold. This helps the researcher to understand how he/she and the research are shaped by the field and relationships within the field (Arber 2006). The research diary offers a space where nascent or emerging ideas can be recorded for future consideration and where things that are poorly understood, or seem to make little sense can be 'flagged up'. It also helps when reflecting upon one's own subjectivity. As such, the research diary can be viewed as a text in its own right (Arber, 2006).

Amongst the techniques employed within a research diary is what Finlay calls the 'telling of reflexive stories' where the researcher 'tells the story' of a particular event or occurrence as a means of working out, or working through what happened and locating him or herself within the story. These may yield interesting insights and offer a means of voicing thoughts, feelings and ideas that might otherwise remain hidden from the researcher or that have no discernible place within the research

process. They 'can open a window on areas that in other research contexts would remain concealed from awareness. In this way, reflexive analysis can give voice to those thought and feeling that are normally silenced. Reflexive analysis also aims to expose researcher silences, things that the researcher leaves out whether deliberately or unconsciously (Finlay 2004). Taylor suggests that:

Writing within a reflexive diary can also be understood as an imaginative endeavour with the researcher taking a step back to see herself/himself as an actor within any given situation, playing a particular role (Taylor 2001a).

Furthermore the writing of a reflexive diary may serve a cathartic function by allowing the expression of anger, confusion or uncertainty. As such it offers a means of dealing with difficult emotional responses or a sense of discomfort such as those arising from the professional/researcher divide (Finlay 2004). For example Arber, used her fieldwork journal to reflect upon her dual identity as a nurse and researcher, and the uncomfortable feelings this identity provoked in particular circumstances. She notes:

One of the most distressing aspects of observing distress is not being able to have an active role in relation to this. By this I meant that a nurse would have a part to play in consoling and comforting the relatives, but a researcher can only witness the distress and write about it (Arber 2006: 154).

In this instance the research diary clearly plays an important role in the expression and management of these difficult feelings.

An important caveat to this, however, is that it is important for the researcher to stay focused upon his/her own subjective experience and the inter-subjective dynamics of research relationships. It is not intended as a strategy for uncovering the 'real' intentions or beliefs of respondents. This would be both theoretically and ethically problematic (Taylor, 2001a, Finlay, 2003). Finally in keeping a diary the researcher is able to become 'an embodied presence to be tracked and placed within the

research as an emotional, feeling subject'. (Arber 2006: 155). This can be part of an audit trail. It may also free up the researcher's writing and become a historical record of the individual's research journey (Richardson, 1994).

3.3 Research design and methodology

3.3.1 The research questions

As stated earlier, the purpose of this research was to explore the language and discourses of HIV and AIDS in India circulating at different levels of the policy process during the early years of the pandemic with a particular focus upon Non-Governmental Organizations based in Kolkata, West Bengal. This section is concerned with identifying the specific research questions. The manner in which the questions are framed reflects both the purpose of the research and the chosen epistemology, which in turn influence the methodology and research design.

The purpose of the research can be broken down as follows. First the purpose of the study is *exploratory*. Sarantakos offers three reasons for undertaking exploratory research:

This research is usually undertaken when there is not enough information available about the research subject. In certain cases it is undertaken to provide a basis for further research...in other cases it is undertaken to gain information *per se*. (Sarantakos 1998: 6).

In this case all three criteria applied. There was, and continues to be a dearth of published peer review studies looking at NGOs working on HIV/AIDS in India. Thus, a piece of exploratory research would be a valuable contribution to knowledge and a possible precursor for further study. With respect to the type of questions arising from an exploratory study, they are concerned with *what* and *who* type questions.

The second purpose relates to the research epistemology. The research aim states that it is concerned with *language and discourses*. This clearly relates back to the chosen epistemology and the linguistic turn in social policy. Further, by using the phrase *in circulation* it is signalling the work of Foucault on power/knowledge. Third, the research topic identifies an overarching theme. This is *HIV/AIDS* giving it a specific disease focus. It also establishes the context of the study, as being *India* in general and then more specifically *Kolkata, West Bengal*. Further it is specifically focusing on *Non Governmental Organizations*. This provides a means of containing the study and offers a lens through which to view the discourses in circulation. The study is concerned with a particular time period and the term *early years of the pandemic* has been used deliberately instead of a specific time frame (e.g. 1986-1991). This is consistent with a discursive approach.

Finally the study is concerned with the *policy process*. Drawing upon the work of Walt (1994), the policy process is used in an inclusive manner. Thus the context, content and actors involved in the policy process are all considered (Walt 1994). The study did not use a linear model to represent the process, conceptualising it instead as something more fluid with the possibility of movement backwards and forwards and up and down. Similarly, whilst there are clear power differentials amongst actors it does not exclude the possibility that power can reside in different sites and be enacted in different ways.

Having broken the purpose of the study down in this manner it becomes easier to reach an appropriate set of research questions which clearly align themselves – as such it facilitates a good fit between the purpose of the research and its theoretical basis. The data collection is guided by the research questions which are as follows:

- What role was envisaged for NGOs working on HIV/AIDS in India at different levels of the policy process?
- How did NGOs based within Kolkata, West Bengal conceptualise the problem of HIV/AIDS amongst their project users and what activities did they undertake?
- How did their activities relate to the role envisaged for them and what factors helped or hindered them in achieving their aims?
- What can this tell us about the different discourses of HIV/AIDS in circulation throughout the NGO community in Kolkata?
- What are the implications of these discourses for policy design and implementation?

3.3.2 Research Design

The research design for this study was a multiple case study approach (Yin 1994). The units of analysis were NGOs working on HIV/AIDS in Kolkata, West Bengal. A number of data collection methods were employed the study, thus it adopted a multi-method approach. This is strongly advocated in qualitative research (Brewer and Hunter 1989:17). The research design included a large component of fieldwork and the distinction is made here between fieldwork and field research. The term field research is perhaps most commonly associated with ethnography and anthropology and with the researchers immersion into ‘the field’ over a long period of time (Bailey 1996: 9).

Whilst the primary focus of the study was upon NGOs, the analytic framework guiding the study incorporated an analysis of the content of policies, the context of policies and the processes involved (see section 3.2). As such data needed to be collected from outside of the NGO, from other actors in the policy process, as well

as from within. In reality at the design stage the full range of actors and institutions that might be relevant to the study was unclear. However some direction was needed to guide this aspect of data collection. Therefore a number of key levels in the policy process, and the actors/institutions associated with each of these levels, was drawn up. At this stage this was not exhaustive. This identification was guided by the work of Walt (2003). The following levels and actors/institutions were identified. At the global level, the World Bank and UNAIDS; at the international level DfID and international NGOs; at the national level the Indian National AIDS Control Organization; at state level the State AIDS Society and the West Bengal Sexual Health Project; and at the local level NGOs. Non-probability sampling was employed based upon selection by non-random means. The term 'snow-balling' is used to describe the approach used (Walliman 2007).

3.3.3 Ethics, informed consent and confidentiality

Before any fieldwork could be carried out, the University of Plymouth, Faculty of Human Sciences, Human Ethics Sub-Committee had to provide ethical approval for the study. This was granted in the spring of 1999. The information provided to the ethics committee is outlined briefly below following the category headings that they stipulated. The implications of these for field-work is discussed in section 3.4.8.

- **Informed Consent:** All participants will be informed at the outset of the nature and purpose of the research. All participants will be given time to consider whether they wish to be involved in the study and to consult further before making a decision.

- **Openness and Honesty:** The researcher will tell all research participants the aims of the research and will not conceal her identity or the reasons for conducting the study.
- **Right to withdraw:** Respondents will be informed of their right to withdraw at any time.
- **Protection from harm:** Every effort will be made to maintain confidentiality, to ensure that all study documentation is stored safely, that the identity of respondents cannot be linked to interview data. Consent forms will not be used because of the potential risk to respondents if their identity should become known.
- **Debriefing:** Study participants will be able to read the final research thesis
- **Confidentiality:** See protection from harm

3.3.4 Identifying sources and data collection methods

The next stage in the process concerned deciding upon the data required and the methods to be used for collecting this data. Discourse researchers typically work with 'texts', which in this context can be defined quite broadly (Bryman 2008, Wetherell et al 2001a). Five categories of text were identified employing a number of different methods. 'Methods are the specific techniques used in social research, tools...' (Payne and Payne (2004). The first category was that of policy documents and grey literature from the various levels of the policy process as identified above. The process of identifying and collecting these was an ongoing one throughout the course of the research.

Second, semi-structured interview schedules were designed for use within NGOs and with key policy-makers and with employees of the selected organizations working

within UNAIDS. A degree of standardization was employed in the design of these, but there was scope for asking additional questions according to the respondent's role. The final design of questionnaires and the process of interviewing was refined and adjusted at the time that the field-work was carried out. Third, in addition to the interviews, data from NGOs Behaviour Change Communication (BCC) literature was collected whenever possible. These included posters, pamphlets, playing cards, visual aids and so forth. This required translation.

The fourth category can be broadly described as participant observation, for example participation at workshops, visits to NGO premises and field visits. Sarantakos offers this definition 'in participant observation, the observers observe from inside the group, and ideally the identity as researcher is not known' (Sarantakos 1998: 208). In the case of this study no attempt was ever made to conceal my identity. As was noted earlier, this study was not an ethnography and for this reason the term field research (as opposed to field work) has not been used. However the bulk of data collection took place 'in the field' and this engagement was often very informal.

'The field' in this case is a symbolic construct occurring whenever or wherever a discourse (or discourses) of HIV/AIDS were in circulation or were enacted in some way. For example, a diagnostic testing centre could be constructed as part of the field, likewise an NGO office, or a truck park where peer educators were carrying out an AIDS awareness intervention. As such, there was no 'field' in the sense of a geographically bounded space. The term informal interview is helpful here to conceptualise these interactions. Bailey notes that informal interviews take place within the field and are reciprocal with both the researcher and respondent (whoever that may be) engaging in dialogue in an informal and unstructured manner (Bailey 1996).

The fifth category of text is that of my own reflexive diary. Whilst I did not think of it at the time that I was writing it as another text, it seems to me now that this played an important role at the time of the study for the reasons highlighted in section 3.2.5.3 These diaries provided a place for me to try to work out and understand my ongoing relationships with research participants and their inter-subjective nature. They were particularly useful in working through difficult thoughts and feelings relating to my position as researcher, especially at points when I felt uncertain about what was going on or how to proceed. These diaries have also played an important role in the process of revisiting my research in the months following my viva. In particular, they have enabled me to look back over the research period and to engage with myself and my inter-subjectivity thus offering new insights and reflections upon myself as embodied within the research process. A key theme to emerge from re-reading them has been the ways in which my identity as nurse/researcher influenced aspects of the research process.

Two notable decisions were made concerning approaches not to be taken. First I decided not to carry out ethnographic research. As Shore and Wright note:

The sheer complexity of the various meanings and sites of policy suggests that they cannot be studied by participant observation in one face-to-face locality. (Shore and Wright 1997: 14).

Second, I decided not to carry out focus groups discussions with members of targeted groups or with individuals affected by/infected with HIV. There were several reasons for this. Predominant amongst them was the need to be realistic about what could be achieved in the time available.

3.3.5 Data analysis: Foucault and genealogy

'Genealogy' is the term used by Foucault for his methodology for examining the discourse/power/knowledge triad. Foucault does not set down a clearly defined means by which to undertake a genealogical analysis. Carabine (2001) suggests that this approach to social research can be understood as offering a lens through which to read discourses. Foucault's genealogical approach is premised upon certain beliefs. First, Foucault believes that discourses produce the objects of which they speak, for example sexuality, madness or unmarried mothers. Thus it can be argued that discourses within policies designed for preventing the spread of HIV/AIDS produce as their putative object people at risk of contracting HIV/AIDS. People within this category can then be assigned certain attributes or characteristics. Second, discourses have power effects. They establish what is 'true' at any particular moment in time. Third, they are 'fluid and opportunistic' (Carabine, 2001: 269) and can hook into commonly held beliefs and normative ideas, about sexuality for example. Discourses also play a role in normalization by conveying messages about what constitutes 'the norm' (Carabine, 2001: 277).

Against this background I drew upon the work of Carabine (2001) to guide my analysis of the data and accounts within this study. Carabine discusses and describes how she used this approach to analyse historical social policy documents with a particular focus upon illegitimacy and unmarried motherhood in the early Nineteenth Century. However the approach can also be used to examine contemporary social policy. Carabine notes that exploring contemporary social policy may be easier in some respects because it is easier to identify sources and background information. The language may also be easier to understand hence

lessening the chance of misunderstanding. The caveat to this, as has already been discussed, is that it can be difficult to step outside of the discourse.

Carabine's work details the means by which she carried out this analysis and offers a structured and comprehensive model for conducting analysis of this kind. Once I had read and understood Carabine's approach I used it to guide my own analysis and at points where I felt that my analysis was making little headway I returned to her work. I also photocopied the outline that she gave to her approach and blue tacked it to the wall over my desk as an *aide memoire* and means of keeping myself focused on the principles that were guiding my analysis. The approach that I took to this analysis is detailed below using Carabine's framework.

3.3.5.1 Select your topic:

My area of interest, the topic on which I chose to focus, was HIV/AIDS in India. The research project developed out of a constellation of personal experiences and interests. This is often the case in social research (Taylor 2001a). In the autumn of 1997 a number of newspaper reports in the UK press began to pick up on the potential threat of HIV/AIDS for India and the need to take measures to control the spread of the virus (Lichfield 1997). I had just returned from India where I had been working as a nurse in the medical room of a non-formal school for street children run by an NGO. As part of this role, I had re-designed a health education programme and extended its remit to include information and advice on puberty and sexual and reproductive health. This had raised a number of interesting questions about what could be said, how it could be said and to whom it could be said.

Simultaneously, in another of the projects run by the NGO, two employees were trying to undertake some research on the knowledge and attitudes of project users

and staff members on HIV/AIDS. This was proving to be difficult territory and after some weeks the research was abandoned because the people approached all said that they knew nothing of HIV/AIDS and therefore could not answer the questions. The 'word on the ground' was that people knew more than they were willing to say and that to have heard even of AIDS was to be tainted because only sex workers were being given this sort of information. Unfortunately, this was impossible to prove or disprove but it was part of the mythologizing around HIV/AIDS within the project at the time.

For this reason I was curious about what form proposed HIV/AIDS prevention and control measures might take, and how those infected with the virus would be cared for. Of particular interest to me were the language and discourses of HIV/AIDS in circulation in India. As an undergraduate I had taken courses on colonial and post-colonial theory and these courses had led me to consider how (or indeed whether) the linguistic theories that I had studied as a humanities student could be applied to a real-life problem. HIV/AIDS in India seemed to offer me a means of doing this. However as a subject area it was potentially vast and needed to be contained. Taking the policies around HIV/AIDS as a starting point offered a means of doing this.

Whilst in India I read a number of different reports and accounts of HIV/AIDS in the English language news media, and as was noted above, it was also a topic of conversation within the NGO that I was working for. I also first heard about the West Bengal Sexual Health project through a friend, just before I left India so I was aware in these disparate ways that HIV/AIDS could be a potential problem. However, it was not a focus of my work at the time and I was relieved to be away from the daily heartache and stress of the HIV/AIDS unit where I had previously worked. It was the U.K. newspaper-reporting of the subject towards the end of 1997

that really aroused my interest. I was also beginning to consider the possibility of doing some postgraduate study. I began by identifying as many sources as possible that would give me an understanding of how HIV/AIDS in India was spoken about and by whom. This was very rudimentary. I thought of it as gathering as much information as possible, from as many sources as possible, to offer as many perspectives as possible. Thus an early source was the reporting of the potential for an 'explosive' epidemic in India from UK newspapers -providing an 'outsiders' view of the problem. I was also able to access some reports from Indian newspapers and journals published in English and available in the UK (or on line) for example *Asian Age*, *Indian Today* and *Economic and Political Weekly*. This provided a steady trickle of information. I then started doing data base searches of published academic literature and also began to identify sources of policy documents.

Fairly early on in the process I decided to take HIV/AIDS discourses within policies as my starting point, the lens through which to view meaning around HIV/AIDS in India. At this juncture Walt and Gilson's framework became very useful. It enabled me to conceptualize the policy process as one that stretched from the international and global, to the national, and the local, and to reflect upon how power might be disseminated throughout these different levels and amongst different actors. It also alerted me to the possibility of multiple different discourses potentially overlapping and reinforcing each other but also acting as sites of resistance and struggle. This was (is) an iterative and on-going process. My early focus was strongly influenced by working in India, UK newspaper reports and NACO policy documents which were available on their web site.

In addition to these sources, the field work in India provided me with a range of sources, from interview data, grey literature and Behaviour Change Communication

literature to policy documents and further newspaper sources, academic and lay texts and so forth. I gathered policy documents from NACO, UNAIDS, DFID, then state and local level NGOs. The purpose of this was not to gather an exhaustive list of sources but to look for the different ways that HIV/AIDS was spoken of.

3.3.5.2 Know your data: read, re-read and read again.

After the initial broad sweep I began to take a more focused approach to reading. In particular I was looking to see how HIV/AIDS was spoken of in policy documents with the aim of identifying the objects of discourse - who and what the discourse spoke about. Identifying the way in which HIV/AIDS was spoken of in NACO policy documents was central to this endeavor. As the field research progressed, the West Bengal Sexual Health Project approach also became important as it seemed to be a consistent reference point for NGOs working on HIV/AIDS prevention within West Bengal. One aim of this was to get a better sense of where HIV/AIDS discussion was coming from and how policy initiatives and interventions intersected with, reinforced or in fact opposed particular understandings of HIV/AIDS. I also used my research diary a lot at this stage to flag up anything that seemed to be interesting or which in fact confounded a particular discourse or simply took me by surprise.

3.3.5.3 Identify themes and categories and objects of the discourse

Carabine describes her aim at this stage as being to get an 'overall feel for the data'.

She describes this process thus:

I also began to identify various themes, categories, representations in, and objects of, discourse. This process of interpretation and analysis becomes more finely tuned and nuanced as the analysis develops. In practical terms this means that I noted down every instance where bastardy was discussed, identifying the different contexts, the ways in which the

problem was 'framed', how it was presented and discussed, and the solutions that were recommended' (Carabine, 2001: 283).

In my own research I focused on how was HIV/AIDS spoken of, by whom and within which contexts. I also identified the different ways in which the problem of HIV/AIDS was presented and the solutions offered to this problem. A number of these are given below to give a feel for this stage of the analysis. Obviously there was disagreement between different 'language communities'. For example the problem of HIV/AIDS in India was presented as:

- An imported problem or a problem of other cultures, i.e. un-Indian, by some Indian commentators. Whilst some global and international actors considered it to be already pandemic but being ignored, and others, professionals (doctors for example) saw it is being disseminated throughout the whole population.
- A grave and deadly threat to public health beyond the scope of the state or private sector hence opening up a space for NGOs.
- Associated with poverty and social exclusion.
- A problem for sex workers, migrants and 'deviants'.

It was at this stage that I decided to focus upon NGOs as the primary site through which to view the different discourses of HIV/AIDS in India. Early on in the study, NGOs were identified as one of a number of key organizations that could be used as sites for conducting interviews, others being UNAIDS partner organizations, government bodies and so forth. At this stage, however, the focus shifted to them as the lens through which to explore discourses around HIV/AIDS. Therefore, whilst the framework for analysis remained the same, NGOS and their role in the design and implementation of HIV/AIDS policy became the focus. Again this distillation

and refinement are part of an iterative process whereby I became more familiar with my data and the discourses contained within it.

At this stage I was also looking closely at the policy-process and trying to identify how different discourses intersected with policy positions. For example, I was interested not only, in how NGOs engaged with NACO agenda but also how they were able to resist it, if they so wished. I also looked for examples where there was disagreement with the prevailing discourse, so called 'sites of resistance' where for example an NGO was taking a very different approach to how it worked with risk groups. Specific areas of contestation also became very interesting. The disagreement about rates of AIDS in India became a focus of my questioning during interviews and also something that I looked for in primary and secondary sources. For example I paid close attention to how HIV was described in terms of spread and distribution, whether it was understood as being contained within certain groups, how these groups were spoken about and whether a disseminated epidemic was suspected. With each of these different areas I also documented the processes by which the information had been obtained, who was speaking, whether the perspective supported or challenged the policy responses laid down in NACO policy and how easy or difficult people reported it to be to get their voice heard. In this way it was possible to start mapping some of the power networks, the means by which certain discourses were operationalised and the strategies that were taken to challenge or counter them.

This was an important part of the process because as Carabine notes:

Genealogy is not concerned with seeking the truth, or with finding the *real* sexuality, or the *real* unmarried mother, nor is it concerned with unity or with presenting a correct and full picture of what went before...Rather genealogy is concerned with describing the procedures, practices, apparatuses and institutions involved in the production of

discourses and knowledges and their power effects. For me this is not simply about exposing the processes through which discourses are produced but also about establishing the ways that those discourses are practiced, operationalised and supported institutionally, professionally, socially, legally and economically...Thus we might use genealogy to interrogate present discourse (Carabine, 2001: 276).

3.3.5.4 Absences and Silences

Carabine describes absences and silences as ‘...what is not present or spoken of that you might expect to be’ (Carabine, 2004:285). This can be a tricky area because the researcher too is embedded in discourse. Working reflexively can help. For example health care was the area that to me seemed to be absent and I pursued it wherever possible. What I was less able to identify was the part that I as a nurse played in the overall research process i.e. my identity as a nurse was an absence (see chapter 8).

3.3.5.5 Interrelationship between discourses

The purpose of this phase of the analysis was to try and identify ideas and norms of behaviour that informed and intersected with the discourses of HIV/AIDS and NGOS within the research data and accounts. As such, it included a process of cross-referencing with some of the secondary sources that I had read during the earlier phase of research for example literature concerning gender and sexuality, the social construction of female identities in India, and associated ‘norms of behaviour’ particularly those relating to sexuality and power relationships. Examples include the widely held social norm of pre-marital virginity for women and the symbolic construction of the middle class wife as the locale of family honour, homosexuality as an aberration of Western society not found in India and so forth. These in turn intersected with post-colonial discourses of the nation state and national identity where Indian identity could be juxtaposed with the aberrant West. As such it was

possible to begin to untangle some of the meanings and understanding around HIV/AIDS and to see them as being deeply enmeshed within other discourses about sexuality and nationhood. In doing so it is possible to untangle 'wider issues about power and sexuality' (Carabine, 2001: 302).

3.3.5.6 Context

Understanding the context involves first, outlining the background to the issue and second, contextualizing the material in the power/knowledge networks of the period. In order to carry out this stage I was particularly concerned to identify the key influences on policy development. Walt's framework helped to identify the context, actors and process involved in policy formation:

It is one thing to identify a discourse and its object and to begin to identify its effects. But to fully appreciate its impact and the extent to which it draws upon existing power/knowledge networks or/and creates new ones, we need to embed it within the social, political, cultural and economic context of the time (Carabine, 2003: 501)

There are two final points. First, as Carabine notes, it is difficult to break this process down into clearly demarcated steps. In reality, the analysis is a dynamic process with iterative cycles of interpretation and reinterpretation. Second, the limitations of the research, data and sources must be recognised. This intersects with the earlier section on intersubjectivity and the placing of the researcher within the text.

3.4 Data Collection and Field Work

3.4.1 Time frame of study

The data collection for this study was carried out in three distinct phases. The first from October 1998 to July 2000 included a period of research training, the initial literature review (this was an ongoing process) and the gathering of primary data in the form of policy documents and grey literature. The research design was also developed as far as was feasible. This included developing interview schedules, interviewing two UK-based respondents and seeking ethical approval from the university. The second stage, in effect the first phase of fieldwork, was from August to December 2000. Inevitably much of the contact work with gatekeepers, the selection of NGOs for case studies and so forth took place during the first stage of the fieldwork. The majority of the data collection also took place during this phase. The second phase of field-work was for a shorter period of time, from September to November 2001. This involved some follow up interviews with NGOs and the West Bengal Sexual Health Project (WBSHP) and the collection of a new body of data concerning the care and support of those infected with HIV.

3.4.2 Identifying gate-keepers and key respondents

I was given the contact details of the director of the West Bengal Sexual Health Project (WBSHP) before I arrived in Kolkata. Details about the role and composition of WBSHP are given in the following settings chapter. At the time of the study it was the primary funding and support agency for NGOs working on HIV/AIDS in West Bengal. Therefore this was a significant introduction. Indeed this introduction was to prove to be pivotal to the early stages of my fieldwork. On my arrival in Kolkata the director of the WBSHP was happy to meet me to discuss my

research proposal and was satisfied once the questions of ethics and confidentiality had been covered to provide me contact details of all partner NGOs and where helpful to facilitate introductions. He also granted me access to their resource centre and made available to me any documents that I asked for.

As my research developed, however, it became clear to me that my natural reticence was at times a major impediment when I needed to ask people for help, information or contacts. I was unlikely to push for help or support from people who seemed reluctant to have anything to do with me. I felt no sense of entitlement when it came to calling upon individuals (I now see this as an indication of my own ambivalence about my identity as a researcher) so that at times I felt extremely uncomfortable negotiating my way through these encounters. In some ways however, I think that my reserve helped, because I was often aware of people going out of their way to make me feel at ease. Of course there were also situations where I was worried about imposing myself when, in retrospect, the individual or organization that I had approached saw me as having something potentially useful to offer them. This was most clearly articulated by the director of one NGO who gave me permission to have as much access as I wanted provided that I write a review of the different projects for them. Whilst I felt somewhat compromised by this it didn't seem to me to be entirely unreasonable and I agreed to talk to him again at the end of the study about doing this.

Four other individuals played an important part in helping me gain access to research participants. The first of these was the director of UNAIDS India, based in Delhi who agreed to a lengthy interview and gave me contact details of all co-sponsoring UNAIDS organizations. Interviews were finally conducted with UNICEF, WHO, The World Bank, UNDP and UNFPA. Two fellow PhD students

also shared their contacts with me. In this way I was able to contact a number of individuals whom it may have been difficult to reach and to do so with the personal recommendation of somebody known to them.

The fourth gate-keeper was a doctor whom I interviewed at one of the NGOs. Up to the point at which I met this contact I had been trying unsuccessfully to gain an introduction to the medical director of the State AIDS Society (SAS) and to find out more about the care and support offered to individuals with HIV within the government health sector. What I had discovered was that nobody working under the rubric of the NGO community was either willing or able to give me the contact details that I needed. As a consequence of this I was approaching the end of my first field visit and had a number of perspectives and views on the government health sector's response to the pandemic from within the NGO community but I wanted to add the perspective of state care providers. I also wanted, if possible, to have more detailed information about the extent of the epidemic within West Bengal. I had by this point been told by more than one respondent working within an NGO that the AIDS patients they had seen didn't seem 'that ill', something that I found hard to understand given my own experiences as a nurse. I wondered whether the health sector was actually seeing much more of the actual fallout of the AIDS pandemic than the NGO community but I had no way of ascertaining this without making contacts within the sector. A possible explanation was that they were shielding clients from me who were HIV positive because I was an unknown quantity. It was also possible that because my initial introduction to the majority of the NGOs was via the WBSHP, I may have been viewed by respondents as part of the DFID machinery that provided them with funding therefore there was a need to present a successful face to me.

Whilst one can plan one's research and have a detailed outline to follow, real world events can on occasion change the direction of a study or some aspect of it. Three days before the end of my first field trip I was doing a final round of interviews within the community centre of a large NGO. One of the respondents was a doctor. Later that day she telephoned me and said that if I wanted to meet and talk 'off the record' she would be happy to do so. We met at a polyclinic where she also worked and she gave me the contact details of several doctors, including the medical director of the State AIDS Society, whom, she felt, would be interested in my research and would probably be willing to help me. In this seemingly random way I had the introductions that I needed. However, I had no time in which to contact these people.

It was this single event that opened a number of doors for me. Although it was too late to act on the information I had been given, I contacted the medical director of the SAS and asked if he would be willing to be interviewed if I returned to Calcutta later the following year. There was another sound reason for returning - the WBSHP was on the point of handing over its operation to the SAS and there was a measure of uncertainty and concern being expressed about what this might mean for the NGOs. A subsequent shorter field visit would enable me to revisit these participants and find out their experiences of the handover.

This is a clear example of a situation where my identity as a nurse influenced or affected the manner and direction that my research took because it definitely opened a door for me. In this case I had met the respondent in a drug de-addiction centre and we had talked at some length about the approaches taken including the use of a drug that I knew as an analgesic but not as a heroin substitute. After I left, the doctor had asked the centre manager about me because I had an unusual level of knowledge for

a social work student, which was what she had assumed me to be. This doctor understood that a nurse with a background in HIV would be interested in the health care system and the way in which HIV was presenting. She had colleagues working in the acute sector who were seeing lots of HIV positive patients and thought that by seeing only the NGO side I would be seeing a distorted picture (refer to chapter 8).

Unfortunately I was unable to make contact with anybody from India's National AIDS Control Organization (NACO) despite a number of attempts to do so. I did get contact telephone numbers and addresses but was never able to elicit any response. Again I was reluctant to be 'too pushy' as I perceived it and I also felt that as my visit coincided with the roll out of a new programme people were probably justifiably too busy. I was able to access their policy documents for the National Aids Control Programmes 1 and 2 (NACO 1999; NACO 2000). I also gathered a number of NACO publications and reports from other respondents.

3.4.3 The NGOs

In total 11 NGOs participated in the study. A brief description of the type and range of activities carried out by the NGOs both HIV/AIDS related and other work is given below. In order to maintain confidentiality the names of the NGOs are not given. If an NGO was a partner organization of the WBSHP this is indicated. The NGOs are presented in the order in which they were contacted.

- NGO 1: This NGO was a charitable blood bank and it was also working on reproductive and child health and community and development work around HIV/AIDS. As such it was working on prevention and control with a wide range of targeted groups including truck drivers, brothel based sex workers and high-class call girls. These interventions were carried out in several sites

including at the borders of India/Nepal. It was also working with the SAS in neighbouring states. It had been involved in drawing up state and national level guidelines on the rational use of blood and developing transfusion guidelines to reduce the risk of transmitting HIV/AIDS. It also provided a range of care and support services for PLWHA. Its targeted interventions were not funded by WBSHP.

- NGO 2: A social development and welfare organization working with abused and trafficked girl children and women. It had a number of shelter homes for vulnerable girls and young women and ran community based projects for commercial sex workers and their children. It was also an activist organization and campaigned locally and nationally to raise awareness on issues around the abuse and trafficking of girl children and women. It worked with young women to help them get back into mainstream society and ran vocational training programmes. It had plans to develop a hospice for the care and support of people living with HIV/AIDS..
- NGO 3: This NGO has a large number of health and social welfare projects. It had a specific expertise in working with people who had problems with alcohol and drug abuse and offered de-addiction, harm reduction, detoxification and a night shelter for former addicts. It also provided primary health care to the wider community via clinics and an outreach team. This team visited railway stations, markets and other locales throughout Kolkata and South 24 Parganas. As a partner organization of WBSHP it was running targeted interventions with drug users, migrant workers and railway workers.
- NGO 4: This NGO was a support group set up by and for HIV positive individuals and their friends within Kolkata. It provided free HIV testing and

counselling services, a telephone help line, access to clinical care and social support. It also had close links to a research institution.

- NGO 5: This was a large NGO with formal schools and social developments programmes. Much of their work was focused on supporting vulnerable children (street children, platform children, child labourers, children with drug or alcohol addicted parents and children from red light areas) with a substantial range of activities. It was also working with fishing communities, individuals with drug and alcohol problems and commercial sex workers on HIV/AIDS and sexual health. As a partner organization of WBSHP it was providing targeted interventions to fishing communities and street children.
- NGO 6: This NGO was working with sex workers on targeted interventions under the auspices of the WBSHP. It had an activist agenda and had been instrumental in the creation of a sex worker's forum. This NGO actively campaigned for the decriminalisation of sex work. It had also helped to establish a multi-purpose co-operative society which enabled sex workers to save and borrow money and ran a help-line for HIV positive sex workers.
- NGO 7: This NGO had branches throughout India and provided contraception, sexual and reproductive health services to women. It was involved in providing HIV/AIDS education to schools and colleges throughout West Bengal.
- NGO 8: This NGO worked with men who have sex with men. It was a nascent organization with one paid member of staff and no formal premises from which to work. It had two areas of work. First it was a support and friendship group. Second it provided professional services such as counselling and was working on sexual health and human rights.

- NGO 9: This NGO had started life as a project working with men who have sex with men. It carried out operations research and a needs-assessment but was unable to secure funding to develop an intervention project. At the time of the study it had a number of other projects working with boys who lived in children's homes or remand homes. They were working on issues such as gender and violence with these children offering creative therapies such as drama therapy.
- NGO 10: This NGO had centres in two of Calcutta's red light areas. It provided support and help to the women and children within these communities. This work was broad-based and HIV was approached in an integrated way. They did not conduct targeted interventions (as in the WBSHP model). However, they did provide women with broad-based health services via a clinic and health camps. HIV prevention was one component of this. They also did lots of work with the children of sex workers and were funded by UNICEF to do education work in schools on HIV/AIDS.
- NGO 11: This NGO was well established and had a large office within Kolkata. It worked with street children in the city. It was the urban branch of a large and well-respected rural NGO that worked with women and children. This NGO had children's homes and night shelters. It was a partner organization of WBSHP and was working on HIV prevention with street children, many of whom had been sexually abused, were sexually active and were vulnerable to infection. Their overall aim was to support the children back into mainstream society.

3.4.4 The researcher/nurse divide

Throughout the course of the field work there were times when I found the disjuncture between my former identity as a nurse and the experience of being a researcher difficult to manage, and it was something that I noted frequently in my reflexive diary. This was particularly so when I went on field visits which were by their very nature more fluid and did not rely upon a prepared script in the form of an interview schedule. At times I felt like a spectator or worse a voyeur, looking in on a world in which I had no useful part to play. This echoes well the experience of Ballinger who notes:

My early field notes record my sense of self-consciousness and difficulty in sitting and observing, in preference to being more active. As a therapist I saw many opportunities for what would be regarded as therapeutic activities and interactions (Ballinger 2003: 75)

I also struggled with how much to tell people about myself and this was an area of considerable discomfort for me. There were a number of reasons for this not least my own natural reserve. One interview, that I conducted with a World Bank representative in Delhi, proved to be pivotal in how I managed this issue. The interview was primarily concerned with the World Bank's approach to community and home-based care and support. The respondent had been polite and thorough in his answers. They did not tell me anything that I had not read in policy documents and I was still unclear about how they would be translated into action. At the end of the interview the respondent asked if I had any final questions. I felt really disappointed that the interview had not yielded any new insights. So I asked the question that I had been wanting to ask all along and in many other contexts but had not for fear of 'outing myself'. 'As a former nurse who has worked in HIV/AIDS I don't understand how these plans will work in reality'. The respondent took of his

glasses, smiled and said 'Well as one health professional to another...' and proceeded to tell me a lot of information both on and off the record.

Importantly, for the way in which I carried out further interviews and how I presented myself, the respondent told me that I should tell respondents of my nursing background because it gave me credibility and people would be more willing to trust me. He also suggested (something that as a discourse-analyst I should no doubt have been attune to) that I had an 'easy confidence' with the scientific language and medical details of HIV/AIDS that was slightly inconsistent with my presentation of myself as a 'junior social scientist'. This ironically should have occurred to me earlier after the doctor in the de-addiction programme had contacted me. This did change the way in which I presented myself in as much as I stopped thinking of my nursing background as a secret that I need to keep. Reflecting on it now, it also seems to me that I was asking people to be honest with me whilst at the same time concealing things about myself which clearly did make some respondents suspicious or at least curious about what 'my story' actually was.

3.4.5 Ethics and reflexivity

The need to make choices grounded in a notion of ethical (or unethical) research was an ongoing feature of the research process. This is an inevitable feature of carrying out field-work of this kind (Bailey 1996). A significant issue was that of informed consent. Everybody interviewed was given an overview of where I was from, the nature of the study and their right to refuse to participate or withdraw at any time. However, consent forms were not used. Given the sensitive nature of the research I decided that asking anybody to put their signature to a piece of paper detailing that they were participating in a piece of work about HIV/AIDS could potentially place them at risk - especially if they themselves were members of a vulnerable community. There was no way within the research environment that these forms could have been kept entirely safe.

A further issue was that of how to manage my interactions and relationships with people when 'in the field' but not actually carrying out formal interviews. This dovetailed with another problem that I had in respect of how much to tell people about myself. The very nature of the research meant that I was moving between formal and informal research environments. Initial contact demanded that I talk about myself and my research but the formal interviews needed to follow a pre-arranged script where I didn't impose myself. There were also numerous occasions when I visited projects and spent long periods of time with research participants, perhaps sharing a meal (always a drink) or travelling to an outlying project. People asked me questions and I inevitably talked about myself and asked questions back. Bailey suggests that this developing of a rapport is necessary and inevitable (Bailey 1996).

It also became clear, fairly early on, that the NGO world within which I was moving was a small one - people talked about other projects, people within the projects, other NGOs and things that had happened weeks or months earlier that supported a position or view that they had of another NGO or official. It was a sociable world. Gatekeepers became friends. This was inevitably a happy time for me. It was also clear that people sometimes held out the hope or expectation that I might be able to help them in ways that were impossible, or which blurred the lines of what I considered to be good research practice.

Against this background I decided upon a few ground rules to help maintain an ethical stance. First I never repeated anything that I heard whilst in the field irrespective of what it was and even if it had arisen in general chat. I never joined in debate about the strengths and weaknesses of certain high profile NGOs when with other NGOs regardless of the temptation to do so. Some respondents gave me information in confidence because they wanted me to 'see the bigger picture'. They did this on the express understanding that I would neither repeat it nor include it in my findings. Despite the temptations to ignore this, I have kept these promises. I never made unrealistic offers of help or implied in anyway that I would be able personally help an NGO or individual if I was unable or unwilling to do so.

A final related issue concerns the process of writing about the study and the anonymity of respondents. Whilst an ethical approach to the research demands that confidentiality and anonymity be maintained, in reality it is quite difficult to write in a manner that does not reveal the identity of individuals to other members of the community being studied. I began to recognise my own 'immersion' in the field when I started identifying individuals (whose identities had been disguised) in workshop proceedings and published articles! An added complication was that two

of the NGOs had a very high profile in Kolkata, and one of them internationally. Their discourses of HIV/AIDS were already in the public domain. In fact to write of them without acknowledging these publicly enacted arguments would be to singly fail to acknowledge their respective sites of power.

Ironically a number of other NGOs also wanted this sort of publicity and would, I believe, be really pleased to be named. Not to do so could be seen as further contributing to the fame of some at the expense of others when fame may lead to highly sought after funding. In the end I have decided to name the NGOs in relation to material published in the Indian and international press, and in published books and peer reviewed journals. All other data collected and the organizations or individuals involved remain anonymous.

Much of this intersects with the notion of carrying out the research reflexively. I wrote a research diary and field-work notes which I returned to frequently whilst analysing the data and writing up. For example if I did not like somebody or found a situation difficult, I noted it and reflected on it. Keeping a field diary helped with this, particularly when I was not sure how to proceed - for example when asked for payment in order to conduct interviews in a particular NGO (something that I decided not to do).

3.9 Concluding comments

This chapter has looked in detail at the decisions and choices involved in designing and carrying out this research. It began by discussing the broad aim of the study and the analytic framework employed. This was to explore the language and discourses of HIV/AIDS in circulation within West Bengal. This particular focus emerged from a combination of personal interests and experiences. Having worked on a health

project within a non-formal school in Kolkata I had first-hand experience of the challenges presented when trying to speak of subjects that are socially unacceptable. HIV/AIDS suggested itself as a particularly difficult issue to work on.

Given my interest in language and discourse it was inevitable that the methodology for the study would draw upon post-structural theory. The decision to focus upon HIV/AIDS policies offered a substantial body of texts with which to work. However over time it was clear that further refinement of the study aims was needed. Thus there was a focus upon the role of NGOs within West Bengal. This focus emerged fairly early on during the first phase of fieldwork when it became evident that the work of NGOs offered a discursive space where the interaction between different actors could be explored.

A case study design was chosen for the research with NGOs serving as the units for analysis. There were eleven of these in total and they varied considerably in size and scale. A number of other actors in the policy process at the state, national and international level were also identified. Multiple research methods were used during the study including semi-structured interviews, the collection and analysis of policy documents and grey literature, the collection and analysis of BCC materials and participant observation. Discourse analysis was used to analyse the data, drawing upon the work of Carabine (2001). The research design and the research process, as presented in this chapter represent a large number of choices and decisions. Some of these were made at my desk during the initial design phase. Many others were made whilst 'in the field' and arose from a combination of academic standards and an awareness of good research practice, the advice of my supervisor and, importantly, personal choice. This was particularly so when faced with ethical decisions. As such I was (and am) implicated throughout this study. Inevitably there were points at

which the study could have been carried out differently. Chapter 8 will consider the strengths and limitations of the study methodology. It will also pinpoint any weakness in the design and discuss the implications that these might have had for the research findings. The following four chapters present the findings of this research.

Chapter 4

Constructing Indian AIDS

4.1 Introduction

This chapter is concerned with the discourses of HIV/AIDS in circulation in India between the mid 1980s and 2001, when the final stage of field research for this thesis was conducted. It will examine how different understandings of the problem of HIV/AIDS informed the development of policies and programming and will also explore how HIV/AIDS came to be understood as a problem primarily confined to members of highly stigmatised risk groups. A key belief driving the policy response throughout this period was that members of these groups were predominantly, if not exclusively, already living on the margins of society and thus were unable to access public or private services (NACO 2000). This gave impetus to the development of a role for NGOs in both prevention and control in the form of targeted interventions for high risk groups, the maintenance of human rights, and the provision of care and support for those infected by the virus. In order to understand this role it is first necessary to look at how the problem of HIV/AIDS was constructed within the Indian context.

Focusing on the discourses in circulation necessitates moving away from a linear account of HIV/AIDS policy and programming in India. There are multiple discourses of HIV/AIDS in India that intersect with one another and are open to change, contestation and re-interpretation. Thus Nguyet makes the important point that:

...the story of HIV/AIDS in India is realistically a fragmented narrative punctuated by orientalist, anti-orientalist and self-orientalizing tendencies and is therefore necessarily jumbled, shuffled, and agitated by these political and cultural thrusts. More of a war of positions made up of contrasting and shifting voices than a monolingualistic and unified narrative... (Nguyet, 1997: 67).

For this reason, this thesis adopts the position that the problem of HIV/AIDS in India should be viewed as a site of contested meaning with no one position holding sway. Following on from this neither the state itself nor the organizations and institutions involved in policy and programming should be viewed as monolithic wholes. As Puri (1999) points out, the contemporary post-colonial Indian state may be a bounded geographical territory but it is characterised by 'multiple policies, institutions and discourses' (Puri 1999:11). Again this calls for sensitivity to different voices, both within and across different language communities.

It is also important to recognize the complexity of the policy environment with multiple actors involved at the local, state, national, and international levels (Walt and Gilson 1994, Walt 1994). HIV/AIDS related policies in India have evolved over time and can be seen to have engaged with, and incorporated, global guidelines as well as national priorities and understandings of the epidemic. These national priorities and understandings have at times stood in sharp contrast to the ideas embodied in global guidelines which suggests a dynamic interplay between national and international actors. Therefore it is important to try and understand the processes by which global guidelines were transferred and then adapted for use in the Indian context. Dolowitz and Marsh (2000) offer the following definition of policy transfer:

Policy transfer (variously named lesson drawing policy convergence or policy diffusion) is about the processes involved in the development of programmes, policies or institutions within one political or social system, which are based on ideas, institutions, programmes and policies in another political or social system (Lush et al 2003: 20 citing Dolowitz and Marsh 2000).

As this definition suggests this process is complex and not explained adequately by a rational, linear model, not least because of the role that power and specific interests play in the acceptance or rejection of certain policies at a given point in time (Parkhurst & Lush 2004). It is also not well understood how far coercion plays a part in the transfer of global guidelines (Ogden et al 2003). Policies represent a critical articulation of the problem of HIV/AIDS and chosen responses at a given period in time and offer a useful starting point for understanding how the problem of HIV/AIDS has been framed. This chapter is concerned with the broad trends in policy development at the national level, in particular understandings of risk and vulnerability, and the focus on identifying high risk groups. Subsequent chapters will look at the translation of policies at the state and NGO levels.

Against this background the first part of this chapter, section 4.2 looks at the manner in which the problem of HIV/AIDS in India was spoken about in NACO policy documents, publications and on official NACO website from 1998-2000. These sources provide an overview of the response taken by the Indian government, NACO and its co-sponsors at the end of the first phase of the National AIDS Control Programme (NACP1), and at the inception of the National AIDS Control Programme 2 (NACP2) and locate this response within an explanatory framework for understanding the nature of HIV/AIDS in India. They provide a set of discourses that offer one explanation for, and understanding of, the problem of HIV/AIDS.

Following on from this section 4.3 looks at the way in which the early policy response from within India was grounded in notions of deviancy and un-Indian behaviour, with Indian morality and chastity being juxtaposed with a deviant and promiscuous West. A globalization of categories can be said to have taken place with orientalist, colonial, post-colonial and neo-colonial discourses all implicated in

the designation of Indian AIDS as a problem of minority groups, deviants and foreigners. This is followed by an exploration of the manner in which understandings of the process of globalization within India have incorporated these ideas about HIV/AIDS. Connections are then drawn between the symbolic inscription of the nation state within a time of uncertainty, and representations of HIV/AIDS as a symbolic threat to national security. The implications of this for constructions of risk and vulnerability are then explored, notably the notion of the 'pure' Indian woman as opposed to the deviant 'other' and the corresponding binary opposites of promiscuity/monogamy within policy. Other criteria for demarcating particular groups as 'at risk' are then discussed. The chapter closes by considering what these multiple overlapping discourses can tell us about the process of policy transfer from the global and international levels to the national level.

4.2 The 'problem' of HIV/AIDS in NACO policies.

This section begins by considering the ways in which the problem of HIV/AIDS was spoken about in a number of NACO publications produced during the late 1990's. These publications provide details of the policies for prevention and control for both NACPI and NACP2, and importantly the reasons for the approaches taken¹⁰. As such they provide an account of the official government position on HIV/AIDS in India and the corresponding response at a particular period in time. It is important to note that the 'unofficial' position may have been very different. Notwithstanding this the policy statements are important because NACO policies provided the basis for a strategic countrywide response to prevention and control of HIV/AIDS. Whilst individual states were expected to develop their own responses geared to local

¹⁰ These documents are as follows: *India Responds to HIV/AIDS* (NACO no date), *Country Scenario 1998-99* (NACO 1999), *Combating HIV/AIDS in India 1999-2000* (NACO 2000). The first of these documents reprises the planning and review process undertaken in preparation for the second National AIDS Control Programme (NACPII).

determinants of risk and vulnerability through out this period, the framework within which these were developed were detailed in national levels plans. Similarly, despite widespread regional variations in patterns and rates of infections, leading to the classification of states as low, medium or high prevalence, the overall epidemic status of India by this time was thought to most closely represent the type four pattern. This was the basis for the approach taken to NACP2. This is described thus:

India's epidemic seems to be following the so-called Type 4 Pattern, first described in Thailand. The epidemic shifts from the highest risk groups (commercial sex workers, drug users) to bridge populations (clients of sex workers, STD patients, partners of drug users) and then to the general population (Government of India, 1999: 5).

The late 1990s was a critical juncture in the development of policy and programming in India. The first phase of the National AIDS Control Programme was facing completion and discussions and planning were taking place for Phase 2. Significantly for policy makers the 1997-98 round of surveillance presented a picture of inexorable spread within designated high risk groups. Furthermore, both HIV infection and AIDS-defining illnesses were beginning to emerge in significant numbers amongst the general population (NACO 1999). Surveillance data also highlighted what many doctors already knew, monogamous married women, whose only known risk factor was sex with their spouse were contracting HIV in rising numbers (Gangakhedkar et al 1997). These cases of infection in women, previously thought to be at low risk, were highly suggestive of the epidemic moving outwards and becoming generalised rather than remaining contained within discrete groups. Although significant regional variations existed in terms of rates of infection, the 1997-98 round of sentinel surveillance saw a number of states become classified as high prevalence states for the first time (NACO 1999).

This picture of rapid spread and the concern associated with it was reflected in a number of policy statements at the time. Thus the cover of *India Responds to HIV/AIDS* (NACO no date) carries a quotation from an address made to NACO by the then prime minister, Shri Atal Bihari Vajpayee, 'HIV/AIDS is the most serious public health problem facing India ...AIDS is a global problem-sadly with a strong Indian dimension'. This sentiment is echoed in *Combating HIV/AIDS in India 1999-2000*, which details the approach to be taken in Phase 2:

There is no denial of the enormity of the problem. The prevalence of the infection in all parts of the country highlights the spread from urban to rural areas and from high risk to the general population. (NACO 2000:1).

Here a distinction is being drawn between populations at high risk and the general population essentially establishing them in binary opposition to one another, despite the fact that the general population is also becoming infected also. Further, the updated NACO website contained the following statement, 'Studies indicate that more and more women attending ante-natal clinics are testing HIV positive...' (website last updated March 2000, accessed 4/10/00). Data from ante-natal clinics was intended to provide information about rates of infection in low risk groups this again supports the assertion that infection was not contained within designated high risk groups (NACO 1999). Thus the problem is presented as one affecting all Indians, members of designated risk groups *and* the general public.

HIV/AIDS is also portrayed as a complex problem, one that has implications for human rights and development. The term 'vulnerable' is used in a number of ways that signal an understanding of HIV/AIDS as a problem of development and inequality. HIV/AIDS is described as a problem for 'vulnerable and marginalized populations' specified as 'sex workers, intravenous drug users, men having sex with men, truckers, migrant labourers and street children'. (NACO 1999: 57). These then

are the putative risk groups that have formed the basis for surveillance and targeting. Then it is stated that 'these groups because of their behavioural attributes are prone to contact the infection more quickly and spread the disease in a very short period of time' (NACO 1999: 57). In this manner the concept of vulnerability is subsumed within an understanding of HIV/AIDS based on risk groups and particular behaviours. The most notable of these is 'heterosexual promiscuity' which is consistently given as the main route of infection (NACO 1999, NACO 2000).

Two sets of factors are described as contributing to the spread of HIV, the first 'individual behaviours', the second, the conditions that give rise to these behaviours. These are grounded in poverty, inequality and social, cultural and religious factors (NACO 1999 58). Despite these understandings of the epidemic, and the awareness that the disease is spreading in the 'general population' the later are ignored and the former provide the rationale for targeted interventions. It is 'individual behaviours' that are used as the basis for the approach.

Against this background it is stated that NACP2 will adopt a 'comprehensive and integrated approach to vulnerable and marginalized populations' (NACO 2000: 26). These are, in reality, synonymous with designated high risk groups. The approach will take the form of targeted interventions with these populations and will be delivered by NGOs and CBOs because the groups are understood to be socially and economically marginalized and cannot be reached by other routes (NACO 2000: 58). Thus, despite moving between developmental and behavioural understandings of the problem, and the recognition that the general population are also affected, it is the socially marginalized and poor who are to be targeted. Given this understanding of the epidemic in the later part of the period under discussion, this chapter will now

look at how these risk groups were first identified and the discourses implicated in this process.

4.3 Identifying Risk Groups

4.3.1 Early epidemiological studies and prevailing social norms

When HIV testing began in India in 1985, policy makers were effectively working in the dark. In the absence of epidemiological data, nobody knew for sure who would be affected. Inevitably other sources of information were used to guide the policy response and emerging details of the trends of infection reported in other countries were the only resource available (Asthana 1996). Early epidemiological studies and AIDS case reporting focused on risk groups rather than risk behaviours and suggested two patterns of infection (Kallings 2008). In the first, pattern I (the USA, UK, Western Europe and Australia) infection was predominantly associated with homosexual men and to a lesser extent, injecting drug users and haemophiliacs. Pattern II was identified in parts of Africa and was associated with multi-partner heterosexual contact (WHO 1988), this became known as 'African AIDS' (Kallings 2008). Karnik uses the phrase 'globalization of categories' to describe this process whereby studies from Africa and South East Asia were used as a pattern for studies in India, hence the focus upon heterosexual spread amongst sex workers and truck drivers (Karnik 2001:341).

While sexual practices, and to a lesser extent injecting drug use, were clearly implicated in the transmission patterns identified, this information was not directly transferable from one country to another. Unfortunately Indian health officials had very little reliable information about gender, sexuality and sexual practices to guide them in terms of identifying indigenous patterns of potential risk and vulnerability

(Nag 1994, Priya 1994a, Pais 1996, Sethi 2002). Instead they fell back upon what they already 'knew' about sexual mores and norms of behaviour to identify those who might be at risk. These early discourses of risk and vulnerability hooked into 'common knowledge' understandings of sexuality and gender in India and putative discourses of Indian purity as opposed to Western immorality. The official position was that homosexuality and multi-partner heterosexuality were uncommon and confined to small discrete groups within metropolitan areas (Jain et al 1994, Pradeep 2002, Sethi 2002). Privately, people may have had very different views. As Dasgupta et al note:

Culturally, chastity is highly valued, yet sex with multiple partners is not uncommon, especially among men, both before and after marriage.' (Dasgupta et al 1994: S86).

This clearly distinguishes between the cultural value placed upon chastity as opposed to the lived-reality of people's lives.

Notwithstanding this, AIDS soon became associated with immorality and deviant Western (and subsequently African) life-styles within policy circles (Dube 2000, Arnold 1997). This association with deviancy was not in fact dissimilar to the manner in which the epidemic was being portrayed in the West. Thus from the earliest days of the pandemic, constructions of risk were writing back to a stigmatised discourse originating in the West (Karnik 2001). This was reflected also in the reporting of AIDS in the media as Nag (1994) notes:

Sex is usually not a matter of overt discussion in India, but the threat of AIDS as a killer disease has made it a legitimate topic of allusion in Indian mass media. Much of the underlying assumptions behind the allusions are based on myths and stereotypes which may be far removed from real fact...' (Nag, 1994: 503).

Attempts to better understand the nature of the problem in India began towards the latter part of 1985 when HIV surveillance was initiated by the Indian College for

Medical Research (ICMR) (Godbole & Mehendale 2005). The first studies looked for infection in blood donors, blood recipients and tribal peoples. However, no infection was detected within these groups, reinforcing the official position of government and health officials that it was a foreign problem (Dasgupta et al 1994). The choice of tribal people is an early indication that disadvantaged and discriminated against sections of Indian society might become a convenient focus for testing. Other groups identified as being vulnerable at around the same time included haemophiliacs, homosexuals, eunuchs and sex workers in ports such as Bombay, Calcutta, Madras and Vishakapatnam (Jayaraman 1985)¹¹. It is interesting to note that whilst sex workers have remained a constant category for surveillance homosexuals were interpreted as an imported category with little cultural significance and disappeared from early surveillance programmes. This category was later reinstated as men who have sex with men (see section 4.5.3). The categories of haemophiliacs and eunuchs also disappeared.

The first reported cases of HIV infection were found in commercial sex workers from Chennai (Madras) in February 1986 (Dasgupta et al 1994). The stated aims of this surveillance were to identify the geographical spread of the virus and its major modes of transmission (NACO 1999). However, in reality HIV testing in the early phase of the pandemic was both unsystematic and highly punitive. Indeed, testing practices throughout the time frame of the study have been strongly criticized for ignoring human rights (Bharat 1999, D'Cruz 2003). There were two other clearly discernable trends to this testing; the first was that it placed a heavy poverty focus (Priya 1994a), the second that it targeted foreigners or those believed to have had contact with foreigners.

¹¹ The terms 'eunuchs' and 'prostitutes' are used in the original article rather than the more appropriate hijra and sex worker.

4.3.2 A foreign threat and an 'un-Indian' epidemic

As suggested above, the perception shared by many Indians was that HIV was essentially a foreign disease associated with Western cultural practices, which juxtaposed the immoral West with a moral, chaste and 'traditional' India. This framing of the problem of HIV/AIDS drove efforts to explain how it was manifesting itself in the Indian context. It was expected that infection would be confined to foreigners or those Indians who had had contact with foreigners either through overseas travel or as a consequence of 'deviant' lifestyles. For example, infected sex workers were said to have contracted the virus through having sex with foreigners (Asthana 1996). Consequently the commonly held view of Indian health planners and politicians was that chaste India would be spared from the foreign epidemic and therefore little action was needed on their part (Pais 1996). This was clearly articulated by the then prime minister addressing a meeting on HIV/AIDS prevention in 1998:

When HIV appeared in India in 1986, everybody thought that this is a Western disease that will be contracted only by sex workers in red light areas, gay men and infecting [sic] drug users. (NACO 1999:2).

Certainly, many health planner and politicians felt that those who might be at risk deserved what befell them. Monitoring the spread of infection within discrete groups was seen as an adequate response for the Indian population (Dube 2000).

Steps were taken to contain the threat posed by foreigners by making HIV testing of foreign students mandatory and deporting those found to be HIV positive. Many of these students were African reinforcing the idea that AIDS was also an African disease (again associated with deviancy), thus further contributing to the othering of the epidemic in India (Asthana 1996). Inevitably when HIV infection was found amongst foreigners this was used as proof that they constituted a risk group despite

the unrepresentative sampling involved. The extent to which the 'foreign threat' was taken seriously is reflected in the call by the then director of the Indian College for Medical Research for sex with foreigners to be outlawed (Dube 2000). An executive order from the government also demanded that all foreign nationals who wanted to stay in the country for more than four months had to have an AIDS-free certificate (Dasgupta et al 1994). With the epidemic being constructed as one of deviancy not normally associated with Indian culture, to be at risk of infection was to be 'un-Indian'.

4.3.3 A globalization of categories and orientalist discourses.

In the early years of the pandemic members of the global public health community were also trying to get to grips with what AIDS might mean for the developing world and there was a growing awareness that HIV/AIDS intersected with the problem of under-development in two ways. First, under-development gives rise to conditions that increase vulnerability and susceptibility to infection. Second, AIDS has the potential to undermine any progress already made in development (Barnett & Whitehead 2002). India's expanding population was already a cause for concern and debate, both nationally and internationally (Jain et al 1994). The question began to be asked about what an epidemic of African proportions might look like, if it were to develop in the Sub-continent with its significantly higher density of population (Jain et al 1994, Atlas 2005). Thus parallels were drawn between the epidemic of AIDS in Africa and the potential for a devastating epidemic in India (Pais 1996). The unfolding problem in Sub-Saharan Africa was explained in terms of multi-partner heterosexual spread, with commercial sex workers and truck drivers implicated in spreading AIDS along the highways (Patton 1992, Pais 1996, Sidel & Vidal 1997). This was used as a model to explain one possible pattern of the

epidemic in India, where it was known that major cities had considerable populations of sex workers (Karnik 2001, Pais 1996, Rao et al 1999).

Karnik (2001) suggests that this response to HIV/AIDS needs to be understood in relation to hegemonic discourses originating from the West and the a priori assumptions upon which they were founded, particularly in relation to ideas about Indian culture and disease. Earlier it was suggested that a globalization of categories took place in the mid 1980s when attempts were first made to understand AIDS and its possible implications within the Indian context. This globalization of categories originating from the West engaged with orientalist discourses of the exotic and pestilent East to produce 'an exotic theory of epidemiology' (Karnik 2001:335). As part of this process, ideas about deviant sexuality came to the foreground, hence the focus on sex workers and truck drivers (Karnik 2001).

Thus, it can be seen that two significantly different understandings of the epidemic in India began to emerge, in policy circles at the international and national levels. The first, originating from within Indian, engaged with globalised categories of risk and found them to be the antithesis of prevailing beliefs about Indian culture and sexual mores, thus the perception that India was not at risk from something that was essentially a 'foreign' disease. When infection began to emerge in discrete populations that were already highly stigmatised, this was linked to immorality and transgression from Indian cultural norms further entrenching their stigma and the perception that Indians not located within these groups were not at risk. The second understanding of the problem focused upon comparisons with the epidemic in parts of Africa, the role played by sex workers and truck drivers in its spread and the potential for India to become the most AIDS infected country in the world (Jain et al 1994, Pais 1996). This understanding was strongly criticised within India as being

grounded in an orientalist discourse with its roots in cultural and racial stereotypes (for example see Cowley 2002).

4.3.4 A controversy over figures

The tensions outlined above, were played out in disagreements over rates of infection for HIV/AIDS in India. This was a highly contentious subject with considerable disagreement amongst actors at the national and international levels about which projections most accurately reflect the true extent of the pandemic (Sethi 2002, Singhal & Rogers 2003, Economist 2004). The Indian governments' position throughout this period was consistently that the estimated and projected rates for HIV infection were too high and that figures produced by NACO were more accurate than those produced by WHO/UNAIDS (Sethi 2002, Singhal & Rogers 2003). Similarly the Indian government's estimates of HIV disease burden and those produced by the UN were different with the latter proposing higher figures not accepted by the Government of India (Goddbole & Mehendale 2005).

This controversy was read at the time in different ways and used to support or reinforce widely divergent views about the status of the epidemic in India. The lack of consensus about figures enabled diverse groups to use data to support their own position, and the disagreement about data was incorporated into a number of competing discourses. This controversy over figures was picked up by the media both within India and abroad (Prasannan 1998, Economist 2004, Economist 2007).

For example one Indian newspaper summed up the situation thus:

India may be the world's largest reservoir of HIV. Or may not be. The truth is no one really knows how large-or small- the figure is. ...Halfway through the year 2000, no one is sure who is right. Or are they all wrong? (Mudur 2000: 1)

4.3.5 The 'most infected mantle' and the spectre of African AIDS

Two points emerge from reading newspaper reports of the time. The first is that India's designation of 'most AIDS infected country' was being reported in the press as was the response to it at the government level (Bollinger et al 1995). The second is that this was explicitly linked to representations of the AIDS epidemic in Africa and comparisons between the two epidemics (Lewis & Bamber 1997, Economist 2007). During my field research this issue about the 'true' extent of the epidemic was one that I raised with respondents. I realize now, that it was a report in a British newspaper suggesting that India might have the highest number of citizens with HIV that contributed to my interest in the area, and I subsequently used this to support my assertion that the study had relevance and was worthy of pursuing¹².

The most AIDS infected designation upset politicians and was strongly resisted at the national level (economist 2007, interview data UNAIDS). However, the linking of India to Africa was used frequently as a potent symbol of what the future could hold for India. The spectre of 'African AIDS' informed early thinking at the global level with the possibility that if the AIDS epidemic were not brought under control it might grow to 'African proportions' (The economist 2007). A post- colonial reading of this from within India argued that this representation was racist in origin (Prasannan 1998). Yet ironically, by the late 1990s the spectre of 'African AIDS' was also being used by Indian politicians as a potent symbol to signify the potential threat to India and as a justification for the approach to policy being taken¹³.

¹² 'In India, the infection rate remains small, in proportional terms, only 1 per cent of the adult population. But this represents up to 5, 000, 000 people making India the country with the largest number of HIV victims in the world'. The Independent 27th November 1997- *Lethal Epidemic is much larger than feared*.

¹³ See for example the speech by Sri Atal Bihari Vajpayee to Indian's NACO 'I have taken the liberty of referring to Africa and quoting president Mandela because our situation is also alarming...' (NACO 1999: 1)

4.3.6 Counter discourses and post-colonial readings

Disagreement about rates of infection and HIV related disease burden needs to be situated within the evolving understandings of the epidemic, both at the national and international levels and emerging discourses of HIV/AIDS. For example, orientalist discourses, such as those described above, were challenged by post-colonial readings of the epidemic and policy responses to it. One such response was to argue that the manner in which the problem of HIV/AIDS was framed in the policies and best practice of international institutions was, on one hand, a form of post-colonial racism, and on the other hand a neo-colonial attempt to take control of India's indigenous health policy as a means of securing new foreign markets. This counter discourse took as its starting point the assertion that the projected figures for rates of infection were too high and signified the biased and inappropriate application of methodologies designed for use in a very different context (Prasannan 1998, Mudur 2000). The argument follows, that India, whilst entirely different to Africa, was chosen because of orientalist understandings of race and the homogeneity of cultures and was, therefore, based on racist stereotypes. It was also argued that figures had no basis in fact and instead of allowing the Indian government to set its own priorities for public health spending the agenda had been externally imposed (Baru & Jessani 2000). Thus the World Bank and IMF were charged with skewing the public health agenda, and setting their own priorities because this fitted with the liberalization of the economy and the reduction of state intervention into the health and social sector (Antia 1993).

Furthermore, it was argued that this externally imposed focus upon HIV/AIDS, had resulted in a growing Indian market for foreign goods such as HIV testing kits,

syringes and blood transfusion supplies, and for loans to develop and implement HIV/AIDS interventions. These loans were said to dwarf available funds for other health and disease control priorities set nationally and locally (Priyya 1994a, Mudur 2000, Prasannan 1998). The lack of focus on the provision of ART in policies has to be understood in this context (see pages 237-238). NGOs were implicated in this through their desire to attract foreign funding and were therefore deemed to be co-conspirators in a form of neo-colonial expropriation. This gives a clear indication that the understanding of the term 'NGO' as an organization that does good for others is not universally accepted in the Indian context.

This post-colonial reading of policy responses to HIV/AIDS in India also engaged with colonial discourses of public health and tropical medicine from an earlier era and their employment in the furtherance of the colonial project. Nineteenth century public health has been understood as a tool of empire employed to further subjugate and regulate colonized peoples and as a justification of the process of colonization. As Harrison notes 'public health measure have been viewed as powerful tools for the domination of indigenous people...' (Harrison 1994: 3). Furthermore the body of the colonized can be read as the site of conflict between the colonial power and indigenous politics (Arnold 1988, Arnold 1993). A prime example of this can be seen in the Contagious Diseases Act (Balhatchet 1980)¹⁴. Seckinelgin (2008) suggests that vertical policies such as these were indicative of vertical socio-political relationships between the colonizer and colonized. Today's vertical policies are both

¹⁴ The Contagious Disease Act was passed by the British in 1868 for the regulation of sex workers, namely the compulsory registration of brothels, compulsory medical examinations and the treatment of prostitutes with STIs in lock hospitals. The forced testing of sex workers for HIV can be seen to refer back to this earlier period of enforcement and control, where it has been argued the mechanisms for this type of social control were first put in place (Arnold 1993).

a legacy of this colonial past and the colonial thinking imbedded in current vertical socio-political arrangements.

Ultimately, this disagreement about rates of infection should be read as a competition not simply about absolute numbers but rather over who ultimately has the right to define the problem of AIDS in India. During the time frame of this study the epidemiology of HIV/AIDS became a site of contested meaning with no one position holding sway. It opened up a discursive space that enabled people to argue that the epidemic was either abating or exploding. It also reflected the shifting nature of power between different policy actors and institutions. Further it enabled aspects of policy, for example the role of NGOs to be challenged.

4.4 Globalization and constructing the nation-state

4.4.1 Introduction

These orientalist, colonial, post colonial and neo-colonial discourses need to be situated within the context of the post-Independence project of nation-building and India's changing economic and political climate since the 1980s. In the post independence period India followed a 'middle path' for its economic development- the 'Nehruvian' model based upon five-year plans, public sector financed industrial development, a closed economy, non-aligned foreign policy and state-led development (John 1998, Sarkar 2008). By the mid 1980s, however, India was facing an economic crisis and had started along a path of economic transition. The liberalization and opening up of the economy in 1990 represented a significant challenge to the philosophical basis of what had come before, as well as heralding significant changes to the political economy of India (John 1998). These changes included structural adjustment with a reduction in state financing for health and social welfare, a pro-American foreign policy and the insertion of India's economy into global markets (Sakar 2008). Nor were these processes of globalization purely an economic phenomenon as John notes:

...there has been a tangible sense of the 'liberalisation' and 'globalisation' of sexuality ... if the inroads of multinational capital have been a cause for concern, the effects of the sexualization of the visual field are perceived as being positively alarming (John 1998: 368).

Against this background, and faced with a perceived loss of national identity brought about by these sweeping economic changes, sections of the Hindu Right adopted a political platform that emphasised Hindu cultural and religious identity as unifying symbols of the nation state. This process incorporated a reaffirmation of the purity of Indian culture and a corresponding identification of 'alien sexualities'

(John 1998; 390). This identification occurred along religious lines but also involved the reaffirmation of an idealised Indian sexuality.

Is it possible to draw any links between Indian experiences of globalization, as described above, and Indian understandings of HIV/AIDS? HIV/AIDS began to emerge as threat to public health in the mid 1980s and can be said to have followed the same trajectory as the opening up of the economy (Singhal & Rogers 2003). The HIV/AIDS epidemic provided a tangible and highly visible example of how the changes linked to globalization and liberalization were affecting the ability of the Indian state to set priorities for its own domestic policies. Thus concerns were expressed that India was losing the right to make its own decisions regarding health planning (Antia 1993, Bannerji 1993). Related to this the World Bank was believed, by some, to have used undue influence to insist that HIV/AIDS was afforded high priority, even though it did not correspond with Indian priorities in public health (Banerjee 1993, Antia 1993, Banerjee 1999). The content of policies for prevention also provoked criticism for being culturally inappropriate (interview data). More broadly HIV/AIDS was also seen to present an economic threat. As one author notes:

With the unchecked increase in HIV, the economic impact on the gross national product will be devastating as money is spent on health care and not development. This diversion of resources cannot be easily tolerated by the fragile economy, which has only recently opened its international markets and made its currency fully convertible'...(Jain et al: S72).

Further, for some people HIV/AIDS was emblematic of a perceived moral decline that has occurred because of globalization¹⁵. In a previous era, India's closed economy and the maintenance of strict border controls aimed at keeping out foreign

¹⁵ See for example Nath (2009) who makes the following comment in the context of HIV/AIDS and Indian youth 'With the advent of globalization and western acculturation, premarital sex is rapidly becoming common among Indian youth (Nath 2009: 4).

goods, served a dual purpose in that they also restricted access to Western culture. To sum up, some commentators within India associated the changes wrought by globalization with a loss of national identity. HIV/AIDS became emblematic of this, bringing in its wake concerns about the incursion of international institutions into the sphere of domestic policy-making, and concerns about the reversal of economic development. Ultimately then, HIV/AIDS has been understood as a threat to national security (Happyman 2005).

4.4.2 HIV/AIDS as a threat to security- imagining the nation

The previous section explored some of the ways in which the changing economic and political context in India, since the mid 1980s, can be seen to have played a role in constructing HIV/AIDS as a threat to the Indian nation state. In this section I will suggest that this construction of HIV/AIDS, could be used, as one way of symbolically 'imagining' the nation-state. Campbell (1992) argues that the post-colonial state building project in third world countries linked national identity with national security. This is very evident in post independence India where the nation state was forged through the blood shed of partition and where border disputes have continued to the present (French 1997, James 1997). This process of nation building is founded upon the construction of boundaries, both physical and symbolic. Campbell argues that:

The constitution of a state's identity is achieved through the construction of boundaries which serve to demarcate 'an insider' from an 'outsider' the 'self' from 'other' and the 'domestic' from the alien (Campbell 1992: 8).

Das supports this assertion when he argues that insecurity is a highly subjective term and that 'policy makers ideologies may discursively articulate India's nationalist identity vis-à-vis certain forms of insecurity' (Das 2008: 4). Thus the construction of a

given danger can serve to consolidate state identity. In a period of economic upheaval, as described above new means of articulating and managing threats to state security/state identity become important (Runa, 2008). This offers a way of unpicking the manner in which HIV/AIDS is understood as a disease that affects certain groups of people in society but not others. Demarcating those at risk of contracting HIV involves the identification of the other both through identifying an external threat (AIDS as a disease of foreigners) and also an internal threat, hence the identification of indigenous risk groups that are stigmatised. This identification of the 'other' can, in general terms, be seen as fulfilling a symbolic function that serves to demarcate the boundaries of what it means to be Indian (Sarkar 2008). In this way the danger, represented by HIV, can be seen as constituting one aspect of national identity.

Furthermore as John and Nair (1998) write, this symbolic construction of nation-statehood, is also a profoundly gendered undertaking:

If the nation is an 'imagined community', that imagining is profoundly gendered... national fantasies, be they colonial, anti colonial, or post-colonial also play upon and with the connections between women, land or nations...the nation state or its guiding principles are often imagined literally *as* women ...As national emblems women are usually cast as mothers or wives and are called upon to literally and figuratively reproduce the nation (John & Nair 1998: 215).

The incorporation of women into nationalist politics is not a recent phenomenon. In the nineteenth century the British created separate Hindu and Muslim Personal Codes. These legislated around sexuality and the family enabling the colonial state to regulate matters that had previously been in the private domain for example by setting a legal age for marriage, criminalizing homosexual acts between men and outlawing of suttee (Kumar 1993). The basis for this can be found in British colonial mappings of sexual discourses and their insertion into a regulatory framework which represented an 'ideal' of sexual and gendered behaviour. This nineteenth century

colonial discourse legislated the distinctions between different religious communities based upon narratives of sexuality and sexual practice. These codes dovetailed with some traditional forms of Brahmanic asceticism. It has been suggested that they constitute a dominant influence on the regulation of sexuality that has persisted to the current day (Bhatt 2003).

In the pre-Independence period, women were involved in the nationalist struggle. Ghandi explicitly used subaltern groups (women, harijans, peasants and tribal people) and their politics as a central theme in producing a narrative of the nation-state. He did so by linking these different groups to their place within a mythologized, traditional Hinduism founded in notions of purity (Rao 1999: 322). Women, and the symbolic state of womanhood, were used in disparate ways to frame not only accounts and narratives of family and kinship but also to constitute the nation state as it emerged. As Das writes:

The woman's body... became a sign through which men communicated with each other. The lives of women were framed by the notion that they were to bear permanent witness to the violence of Partition. Thus the political programme of creating two nations of India and Pakistan was inscribed upon the bodies of women. 'The sexual and reproductive violence to which they were subjected cannot be understood as belonging only to the discourse of the family: it has to be understood as doubly articulated in the domains of kinship and politics'...(Das 1995: 56)[stress added].

The decision of the Indian state in the post partition period to repatriate women who had been abducted needs to be understood as a symbolic act where the state asserted its right to regulate, control and re-purify. Thus again women's bodies were symbolically inscribed to further a nationalist discourse (Das).

This process of inscription, and re-inscription has continued, with women being used as central symbols of the modern Indian (for some this is synonymous with Hindu) nation state where the pure woman as symbol is used across a wide political

and anti-colonial spectrum (Loomba 1998: 195). Rao (1999) explores the manner in which women have been used to symbolise two widely divergent discourses of nationalism, both of which re-imagine religion and do so through a gendered discourse. In both cases women remain passive and voiceless the symbol not the symbol maker (Rao 1999). Given this emphasis on purity the middle class, upper caste (predominantly Hindu) woman 'is the embodiment of the boundaries between licit and illicit forms of sexuality, as well as the guardian of the nations morality' (Loomba 1998:8). Women represent the tradition that must be preserved whilst simultaneously presenting the threat of transgressive unrestrained sexuality and temptation, hence the need for control and repression (Bhatt 2003).

Despite the rhetoric of this and the foregrounding of women in discourses of nationalism women's rights have not been afforded a high priority. The needs of women therefore, in these nationalist discourses are relevant only in as much as they reflect this imagined nation-state. The Hindu right in its promotion of Hinduvta explicitly identifies feminists as lacking in authenticity, or as an alien cultural concept (Sarkar 2008). Gender identity takes second place to identity based along religious lines. Thus problems and disadvantages relating to women as a group (or a particular sub-group) are marginalized unless they reflect a broader religious issue (Burlet 1999).

4.4.3 Making the connections with HIV/AIDS policy and programming

What are the implications of this for women in general and for their designation within risk groups as they are presented in HIV/AIDS policies? The effect of gender inequalities on women's abilities to protect themselves from HIV infection is well documented, both within the Indian context and internationally (Ram & Singh 1991, Choudhury 1992, De Bryn 1992, Long 1996, Gangakhedkar 1997). In India the risk of contracting HIV was associated with particular groups, thus sex workers have been

particularly implicated in the spread of HIV (Pais 1996, Jain et al 1994). This association of HIV with sex workers led to the pervasive belief that women were responsible for spreading the disease (Ram & Singh 1991). Consequently a gendering of the epidemic took place early on which drew heavily on existing discourses of deviancy.

In this context, the symbolic dualism of the pure Hindu wife and the defiled 'other' can be seen to be reflected in constructions of promiscuity and monogamy. These constructions informed policy documents, newspaper reports and health education materials and offered a means of explaining who was, or was not, at risk of catching HIV. The primary means of spreading HIV was understood to be through heterosexual promiscuity (NACO 1999) hence the focus upon sex workers. Therefore women who were not sex workers became members of the residual group (the general population) believed not to be at risk of infection. However from early on in the epidemic 'other' women, women not engaged in commercial sex were becoming infected (Ram & Singh 1991, Gangakhedkar et al 1997).

The problematic nature of this formulation was evident in the ways in which monogamy was spoken about in relation to HIV/AIDS. First monogamy and marriage were frequently linked, for women one was synonymous with the other (Gangakhedkar et al 1997). However, the dual ideal of marriage and monogamy is not enough to prevent women from contracting the virus. Linked with this was the idea that when women (other than sex workers) did contract HIV it was '...with no risk behaviour of their own' (Godbole & Mehendale, 2005:364). The phrase 'no risk behaviour of their own' encapsulates the problem because married monogamous women do have a risk behaviour if their husband is HIV positive, or not monogamous, and they have unprotected sex. To state the obvious, monogamy is

not a protection against infection, if only one of the partners in a sexual relationship is monogamous. This raises the issue of how to negotiate safer sex within marriage.

This promiscuous/monogamous dualism in policies can be read as a coded reference to particular types of sexual behaviour that either conform to a putative 'Indian' sexual morality or contravene it. As such, policies can be seen to have a regulatory and normalizing function and represent an idealised 'Indian' sexuality (Puri 1999). Orientalist discourses may have questioned the validity or 'truth' within these shared constructions of a pure Indian subject, and attempted to undermine them by ascribing different sexual traits and behaviours to the populace, however the Indian state had the capacity to reject these discourses. Part of this rejection lies in the monogamy/promiscuity dualism which allows the state to accept that HIV/AIDS is a threat, whilst at the same time, locating the threat within the body of the 'other' - the non-pure, un-Indian subject. This could be a foreigner or a symbolically-drawn citizen behaving in an un-Indian manner. In this way NACO policies were able to re-work the purity/defilement dichotomy along the lines of promiscuity/monogamy and in doing so symbolically restore and reaffirm national identity and honour. AIDS prevention strategies were criticized in India for promoting particular practices that were 'un-Indian' and culturally unacceptable (interview data). However words like 'promiscuous' remained in the policies as a means of re-orientating the reader to alternative interpretations of these imported prevention strategies, and signalling that certain behaviours were still not acceptable in the Indian context.

4.5 Indian AIDS: discourses of deviancy and poverty

4.5.1 Introduction

What were the implications of this focus upon promiscuity and deviancy for understandings of HIV/AIDS in India? Once this correlation between immorality and vulnerability had been made it was presumed to apply in all cases and heavily influenced which groups were marked out for surveillance (Priya 1994a). Thus when HIV was first detected in paid blood donors, voluntary blood donors and hemophiliacs only the first category was identified as a risk group (Priya 1994a). The immediate assumption was that they had become infected through drug use and promiscuity (Asthana; 1996). Priya (1994a) argues that the categorization of risk groups was arbitrary, placed a burden upon socially marginalized groups without much scientific basis and showed little effort to check the assumptions imported from international experience. Thus injecting drug users and truck drivers already had stigmatized identities but this stigma was further compounded.

The manner in which truck drivers were spoken about both in academic journals and the mass media has reinforced this stigma (Singh 1999, Singh & Malaviya 1994, Sircar & Tewari 1996, Rao et al, 1999). For example Jain et al write 'Another mechanism for exposure of populations in the interior of India to HIV is via truck drivers, *a group well known for their use of CSWS*' (Jain et al 1994: S69) [stress added]. This stigmatizing discourse was already having material consequences for truck drivers at the time of the study. They had become synonymous with HIV infection to the extent that in some parts of India they faced problems in finding prospective wives (Chatterjee & Sahgal 2002). There was also a tendency to generalise within and across group so that differences in working patterns, for

example, were not recognised. This tendency towards generalising about group members is discussed further in section 4.5.2.

The lack of accessible and reliable information for the population as a whole further compounded the problem. Attempts at raising awareness amongst the general population tended towards the use of alarmist warnings and scare mongering in an attempt to bring about behaviour change (Priya 1994a, Dube 2000). During the period of this study there were very few treatment options available and little hope was offered to those infected or who feared infection. The media was quick to pick up on this (Sethi 2002). The printing of lurid scare stories often with the identities of people unchanged or with incorrect scientific and medical information was the only source of information for many people (Patnaik 1998a, Patnaik 1998b, Chauhan 1998, Chattopadhyay & Banerjee 1998).

4.5.2 The Poverty Dimension

Following on from this, this section will explore some of the issues about the construction of HIV/AIDS as a problem associated with poverty and how this helped to create categories of risk that were essentially based upon occupational groups. This in-turn foregrounds some of the tensions inherent in constructing group identities where none exist. The section finishes by looking at the manner in which the identification of men who have sex with men exemplifies some of these issues. The painting of the HIV/AIDS pandemic as un-Indian and arising as a consequence of promiscuity and immorality was relatively easy to disentangle. More complex is the manner in which poverty has, over time, seemed to become a defining characteristic of HIV infection. Poverty is undeniably a key factor in vulnerability to infection (Zwi & Cabral 1991). This is because of the constraints that it places upon life choices amongst other reasons (Mahal & Rao 2003). However attempting to

draw a direct connection between poverty and HIV infection is problematic. Rao Gupta et al (2008) note that the link between poverty and vulnerability to HIV has been drawn in part, as a response to the spread of the infection in Sub-Saharan Africa. However, this relationship is not straightforward because, for example, it is the wealthiest nations within Sub-Saharan Africa that have been most affected. Looking at the Indian context, in a study of long-term illness and death among adults in labouring low-caste groups, the researchers found that 'those who are viewed as poor and lower castes are not all equally susceptible to HIV infection'. In this study HIV infection was found in a cluster of individuals from better off families (Priya & Sathyamala 2007: S42).

With so much emphasis placed upon vulnerability arising from poverty it is little surprise that policy responses, particularly care options, were strongly targeted at poorer sections of society. However, it needs to be understood that HIV infection was not restricted to the poor in India (Dube 2000). For example at the time of the study increasing rates of HIV infection were being found in university students (interview data UNAIDS). That HIV was not simply located within poorer sections of society was acknowledged in the World Bank's project appraisal document for NACP2. Justifying the focus of its policy on the poor because of their inability to afford treatment the report noted that 'there is no clear evidence from India to suggest that HIV/AIDS infection rates are disproportionately higher amongst the poor' (World Bank 2003: 11).

It is impossible to say the extent to which caste played a part in this link being drawn between poverty and vulnerability, or indeed, whether poverty per se carried a heavy burden of stigma. It is probably fair to say that the members of some occupations were drawn from a particular jati group and that their job marked them

out to others as having particular caste associations. However, the rationale sometimes given for why risk or vulnerability was inherent within a given occupational group, travelling or spending long periods of time away from home for example, may have apply to many other untargeted occupations. Truck drivers were targeted, for example, but other occupational groups who travel widely in the course of their work, e.g. businessmen, politicians and airline pilots have not (Priyya 1994a). The critical determinants of this identification appear to have been pre-existing stigmatised identity and poverty.

Furthermore this identification of risk groups which link specific occupations, poverty and in some instances mobility assumes a shared or common identity where none may actually exist. These groups don't necessarily have a shared identity that is meaningful for group members, and there may be significant differences between members of groups that go unrecognised. Studies on sex workers for example have found that younger women are less likely to be able to negotiate condom use, than older women and therefore be at greater risk of contracting HIV (WBSHP 1999c).

4.5.3 Men Who Have Sex With Men

The identification of men who have sex with men as a risk group exemplifies some of the difficulties inherent within assigning people to a particular group. In India, masculinity is synonymous with marriage and procreation. Intimacy (whether social, sexual or both) experienced between men is understood in many ways. Thus a man may have a sexual relationship with another man (or men) without considering himself to be homosexual. Some men may seek to delay or prevent the inevitability of marriage. However, for many men who have sex with men marriage is an inescapable social obligation (Pradeep 2002). Against this background homosexuality is highly stigmatised in India and associated with Western lifestyles

(Jain et al 1994). This stigma was evident in early responses to the pandemic, when it was denied that homosexuality existed in India (Jain et al 1994, Sethi 2002). Confusion has also been caused by the use of terms such as 'gay' or 'homosexual' that may not have cultural salience, hence the adoption of the term 'men who have sex with men' for use in public health. Notwithstanding this it is clear that there is a significant population of men who have sex with men in India (Pradeep 2002) and studies suggest that a considerable number of them, have sexual relationships with regular and non-regular female partners as well as with male partners (UNAIDS & WHO 2007). This has led to men who have sex with men being identified as a risk group (NACO 2008).

The 'take up' (or rejection of) globalised categories (in this case men who have sex with men), can be seen in the interaction between different policy communities (including activist groups), and the understandings that flowed between them at the local, national and international levels. 'Homosexuality' as a category was not explicitly taken up by policy makers, and did not feature prominently in early epidemiological studies (Jain et al 1994). Although it was evidently recognised that there were men who were having sex with men this rejection of the category at the national policy level reflects an explicit unwillingness to engage with the issue (interview data). When NACPI included men who have sex with men as a risk group the category was imported from the global level. Notwithstanding this, the issue was reframed in the Indian context by activist groups, and community based organizations as a human rights issue (Ghosh 1998). NGOs and human rights groups both Indian and international, were involved in this process and in the campaigning for legal rights for men who have sex with men.

Notwithstanding the importance of this, the term 'men who have sex with men' can however be seen as problematic when used in the context of targeted interventions. Men who have sex with men do not constitute an obvious group whether in terms of self-identity, group identity or with respect to visibility. The increasing recourse to sub-dividing men who have sex with men into groups according to sexual behaviours, (for example khoti and panthi) has also been criticised for creating the categories that they purport to describe (Boyce 2007). This reflects the difficulties experienced by policy makers in attempting to deal with the potential for the shifting nature of human sexuality within policies that demand clearly demarcated boundaries with respect to behaviours, identities, geographical locations and so forth.

Another factor that had a bearing upon working with men who have sex with men was that of their 'invisibility'. In India the ability to blend in or pass, is a necessary survival strategy in an extremely hostile and homophobic climate (Human Rights Watch 2002, interview data). The separation of male and female spaces means that many men don't relate socially to women, there is however a homosocial bond (Pradeep 2002). Men are able to display physical affection to one another in public spaces without this being construed as having a sexual basis. Boyce notes that in India '...male-to-male sexuality has been described as both heavily stigmatised and implicitly tolerated' (Boyce 2006: 79). This signals some social latitude for sexuality between men. However, targeted interventions by their very nature risk drawing attention to men who have sex with men and can upset the local balance of accepted (or overlooked) social and sexual interactions between men. Human rights groups and NGOs reported increasing numbers of attacks on men who have sex with men in public places (Human Rights Watch 2002, Paul 2007). Until very recently, this

situation was exacerbated by the legal position of men who have sex with men with homosexuality and 'unnatural sex' being designated as offences under section 377 of the Indian penal code (Rajkhowa 2002: 175). This law was recently repealed marking a significant shift in the legal status of men who have sex with men ¹⁶.

4.6. Discussion and concluding comments

This chapter has explored in detail how the problem of AIDS in India came to be defined as one that was restricted to members of particular designated groups and the discourses implicated in this process of identification. Indian politicians, policy makers, the medical establishment and the media, all to varying degrees and at different junctures, attempted to resist imported categories and refute the assertion that AIDS represents a tangible threat to India. This has meant that AIDS has been constructed as un-Indian even as it was seen to be spreading in India. Against this background, attempts to demarcate the dimensions and spread of the disease were founded upon identifying risk groups. Pre-existing stigma, poverty, and gender inequalities were all implicated in this process of identification.

The initial policy response in India was developed within a context where little was known about the actual contours of the pandemic or how risk and vulnerability were manifesting themselves. At this critical stage the pandemic was characterised as being un-Indian, and arising from deviancy associated with certain types of Western lifestyle, that were believed to be uncommon if not entirely absent in India. As such Indian politicians and health officials were 'writing back' to a stigmatising discourse originating from the West. Consequently infection was looked for in groups already

¹⁶ During the field work for this study the repeal of this law was a central demand of activists engaged in promoting the human rights of men who have sex with men. However it seemed very unlikely to ever happen. That it has, is a cause for celebration, unfortunately it is beyond the scope of this study to explore in any detail the processes by which this change in the law was brought about.

marked out by stigma such as sex workers and truck drivers. Despite advances in sentinel surveillance the correlation between infection and deviancy persisted. Poverty also became a critical determinant in the identification of risk groups. Whilst the specific determinants of risk and vulnerability associated with poverty are well articulated, there is no evidence to suggest that HIV is restricted to the poor and socially marginalized.

What does this exploration of discourses of HIV/AIDS in India can tell us about the process of policy transfer? The long drawn out disagreement over rates of infection and HIV disease burden, offers some insights into the manner in which disagreements between national and international actors were managed. Whilst the Government of India was locked into a particular design for HIV/AIDS programming as a result of funding conditions, it was able to strongly resist the WHO's figures, and was able to assert its own position regarding rates of infection. The consistent refusal to accept estimated and projected figures from the WHO and UNAIDS was a clear indication that the government of India was not simply the silent recipient of global interpretations of the epidemic, and was able to offer its own definition of the problem of HIV/AIDS. At the national level the WHO was excluded from involvement in UNAIDS for a time in the late 1990s when this issue was high on the political agenda (interview data).

Within India the role of the World Bank in policy design was also widely criticized, and this criticism contained within it broader concerns about, and resistant to, processes of liberalization and globalization (Banerjee 1993, Banerjee 1999, Baru & Jessani 2000). Given that the design of NACPI AND NACP2 was the work of the World Bank it is tempting to blame the World Bank for the focus upon marginal groups such as sex workers and truck drivers. A more nuanced perspective suggests

that in reality the World Bank's technical focus on these groups dovetailed with Indian discourses that demarcated 'pure' women from the defiled 'other'. As such the focus on sex workers in global policies for public health merely restate, or intersect, with this prevailing social norms in India. NACO policies were able to incorporate the model proposed by the World Bank, because this model tallied neatly with Indian understandings of HIV/AIDS.

Thus whilst policies stated that HIV/AIDS was everybody's problem the coded message within policies was that it was not 'us' but those 'other' deviant Indians for whom HIV/AIDS was a problem. Meanwhile, the World Bank by its own admission was reluctant to put too much pressure on the Indian government to take a proactive stance over human rights (World Bank 2003). It is not possible to say whether this reflected the fact that for the World Bank this was also an area of low priority, or whether it was considered to be politically too difficult and potentially too conflictual. These points suggest a policy process that is both conflictual at points but at other junctions relies upon conciliation and accommodation with different understandings and meanings being brought into play within the margins of dominant discourses. Against this background subsequent chapters will explore the role of NGOs working with risk groups in Kolkata, West Bengal.

Chapter 5

The development of HIV/AIDS related policies in West Bengal and the role of NGOs

5.1 Introduction

This chapter is concerned with the context, content, actors and process that have influenced the development of HIV/AIDS policy in West Bengal with a particular focus upon NGOs. As such it is drawing upon the work of Walt (1994) and Walt and Gilson (1994). It broadly covers the time period from the mid 1980s until the end of 2001 when the final stage of field-work for this study was completed. India has a mixed model of health care and the NGO health sector has evolved organically without the planning and oversight of the Ministry of Health and the Planning Committee. It has done so in response to gaps in provision and problems with access (Dave 1991). In recent years, health sector reform has created an enhanced role for NGOs (see chapter 1) and NGOs working on infectious disease programmes such as those for TB and leprosy have been encouraged to integrate their activities into the primary health care structures (Porter et al 2002). Because NGOs are generally smaller and less bureaucratic than government organizations they are seen as having greater freedom and flexibility to respond to local need and can work on controversial and politically sensitive issues. What is more since it is believed that they are staffed by community members they are seen to have greater credibility within a given community with the capacity both to understand that community and to reach vulnerable and marginal groups within it. It is these characteristics that have marked them out for working on HIV/AIDS (Asthana 1996, De Jong 2003).

The role mapped out for NGOs in NACPI was extensive. The prevention of infection within risk groups through the implementation of targeted interventions,

became the explicit remit of NGOs (Chatterjee & Sahgal 2002). Widespread human-rights abuses, both institutional (the police and health-care providers being highly implicated) and at the family and community levels, were beginning to be seen as a major impediment to policy implementation (Barat 1999, NACO 1999, Human Rights Watch 2002, Paul 2007). With their roots in activism and community mobilisation, NGOs were identified as primary agents for tackling the stigma surrounding the pandemic and the discrimination arising from it. NGOs were also expected to spearhead pre- and post- test counselling (Chatterjee & Sahgal 2002).

Against this background this chapter is structured as follows. Section 5.2 looks at the contextual factors that have contributed to understandings of the epidemic. These include geographical, socio-economic and political factors. Section 5.3 discusses the nature and extent of the epidemic, drawing on the available epidemiological data as well as interview data and grey material gathered during the course of fieldwork. Section 5.4 explores the meanings attached to HIV/AIDS amongst policy actors within West Bengal and identifies an emerging discourse of HIV/AIDS as an un-Bengali disease. In section 5.5 the focus turns to the nature of NGO/state relationships. These are discussed in relation to the development of state level HIV policy and programming.

Section 5.6 explores the work of the West Bengal Sexual Health Project. The project is interesting, not only in relation to the model that it developed for targeted interventions, but also because of what it can tell us about the evolution of state/NGO relationships and the involvement of the wider policy community, in developing HIV interventions. The chapter ends with some consideration of three emerging themes. The first relates to the process of policy translation and takes the handover of the WBSHP to the SAS as a case study. This is followed by returning to

the idea raised in chapter 4 that NGO is a claim-bearing label and considers whether the idea that NGOs are organizations that 'do good for others' was accepted within the context of West Bengal. I end by suggesting that in order to understand the nature of how NGOs work they are best understood as fragmented sites or sites of contested meanings. As such they can be seen as having shifting boundaries and their relationships (both within the organization and with other actors and organizations) are constantly evolving and changing (Hilhorst 2003, Mageli 2005).

5.2 Context

5.2.1 Geography, history and economics

According to official sources, West Bengal was identified as a potential high risk state early on in the epidemic. Kolkata was one of the first five cities earmarked for an intervention as part of the medium term plan drawn up by the Government of India in conjunction with the WHO in 1989 (NACO 1999). It was recognised as an important city because it has a major seaport and airport and there is considerable cross-border movement from Nepal and Bangladesh (Ojha 1999). Kolkata is also the main port of entry to North Eastern India, and a direct flight to any one of seven North Eastern States takes only an hour. Three of these states, Manipur, Mizoram and Naga Land have common borders with Myanmar (Burma), a major producer of opium (Panda 2001). These states have had high rates of HIV infection associated with injecting drug use since the late 1980s (Asthana 1996; Barnett & Whiteside 2002; Sharma et al 2007). There is also significant movement from the impoverished neighbouring states of Bihar and Orissa with people looking for employment or education in Kolkata and along the coast of West Bengal (Ojha 1999, Barnett & Whiteside 2002). This migration of people increases at times of

food insecurity, flooding and drought. Migration of this sort is associated with vulnerability to infection (Barnett & Whiteside 2002).

West Bengal itself has a significant history of poverty and food scarcity with the resultant internal movement of poor and displaced persons looking for employment (Sleightholme & Singha 1996). Kolkata has the second highest density of population in India with high levels of unemployment and under employment (Ojha 1999) and a third of the population live in slums with few basic amenities (Seal 2000). It also has a large and well-established sex industry with a significant number of sex workers located in Red Light Districts around the city. One estimate suggests that there are 4000 fixed sex workers in the Sonagachi Red Light District alone (Jana et al 1998: S101). The city is also a focal point for the trafficking of girl children and women from neighbouring countries as well as poorer areas of West Bengal (Sleightholme & Singha 1996).

Given the implications of cross-border issues for transmission of HIV, it is unfortunate that India has a difficult relationship with Bangladesh concerning border issues, making cooperation on issues such as leaky borders, the trafficking of girl children and women and collaborative HIV/AIDS policy difficult (interview data). While similar problems exist on the Indian-Nepalese border, better inter-state relations had enabled one of the NGOs in the study to join forces with a counterpart on the Nepali side. Innovation in policy design has included flexibility around staff crossing the border, a willingness to develop complementary services including the sharing of Behaviour Change Communication materials in local languages, the development of a shared symbol to represent the condom, and referrals from one NGO to its cross border counterpart.

5.2.2 Political considerations

West Bengal has had a Left Front coalition government (Communist Party Marxist 1) since 1978. This coalition government has an ideological commitment to decentralization in decision-making and local participation (Webster 1992). This corresponds with the decentralization agenda of the Union government as articulated in the Eighth Five Year Plan (1992). This plan contains an enhanced role for local self-government within the Panchyati Raj system. This was intended to increase participation, including that of NGOs and voluntary organizations, in development (Dhesi 1996). This included a role for NGOs in welfare provision (Sen 1999). However there are ideological differences between the Eighth Plan, which identifies NGOs as key actors in this process, and the CPM1 approach to participation that is grounded in 'class struggle'. NGOs are not seen as part of their *modus operandi* (interview data). Bhattacharyya notes that:

The post-Colonial West Bengal has not been rich in civil society in the sense of having secondary associations, but the place of such associations has been occupied by political associations including political parties and their associations (youth, women, labour). (Bhattacharyya 2002: 26).

While ideology might preclude the active or whole-hearted acceptance of NGOs, certain features of governance in West Bengal could actually lend themselves to a more devolved and participatory approach to health service delivery. This has the potential to help with the implementation of HIV/AIDS policy. NACP2 involved the inclusion of Panchyati Raj institutions in the design and implementation of policy (NACO 2000). It has been argued that the West Bengal state government has been very successful in devolving power to the level of Panchyati Raj (Raghavulu & Narayana 1999) and that the panchayats in West Bengal have been the most successful at local government (Bhattacharyya 2002). Therefore West Bengal could have had an inbuilt advantage had it utilized these structures.

In reality, having the structure in place is only the first step. There also needs to be the political will to use it in this manner. One study participant noted that the state machinery was good at 'drumming up votes' and that the same mechanism could be used to promote AIDS awareness if so desired, but to date there had been little willingness to do this. The other feature of governance at the Panchayat Raj level that might help with a devolved approach to HIV/AIDS is that it is believed to be more inclusive thus facilitating wider participation in the political process. However, studies have shown that power-sharing at the Panchayat Raj level frequently resides with the local elite who resist efforts to broaden the base for participation (Webster, 1992; Antia & Mistry 1998). Further, while in West Bengal some advances have been made by tribal communities, women have remained excluded from local power-sharing (Lieten 1999). There was no evidence at the time of the study that members of vulnerable groups were being involved in decision making at this level. It is true however, that two NGOs in the study said that they were working at village level with the Panchyati Raj on sensitisation issues.

The relationship between the UK Department for International Development (DfID) and both the state and union governments also influenced policy development. DfID (and formerly the Overseas Development Administration) has a long history of working in West Bengal. This can be read as a legacy of colonialism (DfID undated). In 1999 Christian Aid produced a report entitled *The Quality of British Aid to India*. This examined the work of DFID throughout India. The report noted that:

The general perception of DfID in India is very positive. The high quality of technical advice and the willingness to be flexible, taken together with the fact that most British aid to India is provided as a grant, make Britain a highly respected donor in India.... (Van Diesen 1998: 2) [stress in the original].

This positive perception may well have helped with regards to the sensitive issue of developing HIV/AIDS policy. Notwithstanding this, during the course of the research I was told that when the West Bengal Sexual Health Project was first set up the response of some politicians was extremely hostile, with key actors being told explicitly that the project was not wanted, that it should be abandoned and that they should 'go home'. Despite this, in the preparation for NACP2, bilateral government agencies were allocated particular states in which to work. DfID has four partner-states; Kerala, Orissa, Maharashtra and West Bengal. Thus the relationship between DfID and the Government of West Bengal has been formalised with respect to HIV/AIDS.

5.3 Understanding the epidemic in West Bengal

5.3.1 Introduction

Echoing the controversy at the national level, opinions concerning the scope and scale of the epidemic in West Bengal were sharply divided during the period being studied. Indeed, opinions were so polarised that some respondents argued that a generalised epidemic had already taken hold, while others cited official data as proof of negligible or low rates of infection. To an extent this can be seen as a consequence of inadequate surveillance strategies. HIV was first identified in an individual in West Bengal in 1986 (Panda 2000) and sero-surveillance started the following year at the School of Tropical Medicine in Calcutta as part of the National AIDS Control Programme. However, the first round of sentinel surveillance was not conducted until 1998 (Ojha 1999).

5.3.2 Sero surveillance

The HIV surveillance undertaken for much of the time under discussion focused on the unsystematic testing of individuals. There was a notable focus upon foreign students, sex workers and truck drivers. Details of this surveillance are sketchy, although some of the NGOs working with sex workers reported that coercion, involving the police, was a contributory factor in women undergoing a test. This relationship between the police and the state in implementing HIV/AIDS related interventions is perhaps best exemplified by the fact that when the SAS moved to new premises in 1999 they were located within the compound of Kolkata's police headquarters. In 1992, a study conducted by the All India Institute of Public Health & Hygiene (AIIPH) was carried out in the Sonagachi red light district to establish the prevalence of STI and HIV infections amongst sex workers. This study, the precursor for the Sexual Health Intervention Project (SHIP), found an HIV rate of 1.1% with five out of 442 samples testing positive (Jana et al 1998: 102).

According to data published by the Sexual Health Intervention Project (SHIP) subsequent surveys in 1993, 1995 and 1998 found HIV prevalence amongst sex workers to be fairly stable at 5.53%. As this publication goes on to say, this is much lower than in comparable communities elsewhere in India (Jana & Banerjee 1999). However, other sources challenge these figures. It has been argued that cross-survey comparisons are inappropriate due to methodological differences between different studies hence the importance of base-line surveys (West Bengal Sexual Health Project 1999c). Dr D.K. Neogi, head of virology at The School of Tropical Medicine, is on the record as saying that 27.3% of CSWS in West Bengal were HIV positive in 2001 and that the rate was increasingly rapidly (*The Statesman* 2001).

Another survey carried out in 1993 by Bhoruka Public Welfare Trust found HIV prevalence rates of 7% amongst truck drivers (interview data). Following on from this, the WHO and NACO became involved and truck drivers were identified as a high priority for interventions. Subsequently DfID set up its Healthy Highways project. Additional data concerning rates of infection can be found in Bhoruka's 2001 annual report. It began testing its donations for HIV in 1992. In the first year of testing 2 samples were found to be positive, this was 0.009%. The following year the figure was 0.03%. This had crept up to 0.18% in 1999 and the sero-positivity rate for the year 2000 was 0.21%. The report notes that 'The alarming rise in sero-positivity of HIV from 0.0009% in 1992 to 0.21% in 2000 is a matter of serious concern' (Bhoruka 2000: 11). The availability of data on these two risk groups, sex workers and truck drivers illustrates the fact that the globalization of categories discussed in chapter 4 was also informing understandings of HIV/AIDS at the state level.

5.3.3 Weaknesses in sero-surveillance

The purpose of sero-surveillance is to diagnose infection in the individual as part of a programme of clinical care and as a HIV prevention strategy. It is not intended as the basis for planning prevention and control activities. For this, sentinel surveillance is needed (Mann & Tarantola 1996). Nor does focusing on a limited number of risk groups further understanding about the manner in which the epidemic may be spreading outside of these groups. This is an issue in the early stages of the pandemic when it may not be evident which groups of people, if any, are at greater risk of infection (Priyya 1994a). It may also contribute to the denial surrounding the epidemic.

Data provided by the State AIDS Society in its 1999 publication *Key Information on Prevention and Control of HIV/AIDS* illustrates this problem. This report contains data about the sero-surveillance carried out in West Bengal from 1986 to December 1999. It reports that a total of 116140 samples were tested during this time frame of which 1 728 were found to be positive. Figures are also provided for the number of cases of AIDS diagnosed between the years 1996 – 1999 (204, 371, 277 and 403 respectively). It is not clear from this source how these data were gathered. This document provides a 'sero positive breakdown' which includes a large number of groups (Ojha 1999:19). These are; homosexuals, haemophiliac/recipient of blood-blood products, foreign students and others, suspected AIDS/ARC patients, IV drug abuser, promiscuous persons, STD patients, prostitutes and pimps, ante-natal mother, relatives of AIDS patients, patient with chest disease, truck drivers and helpers, patient on dialysis, sailors, foreign going Indians, other Eastern States and other diseases (Ojha 1999: 19).

Because of the unsystematic nature of this testing and the lack of information about the data it is impossible to draw any conclusions about who might constitute a risk group (and who might not). Given that these groups are so wide-ranging it does beg the question of who might make up the 'residual' category of the general population. Three broad trends can be discerned in the composition of these designated categories. First there are the risk groups identified at the national level, notably foreign students and others, sex workers and pimps, STD patients and so forth. Second, there are a number of categories that suggest some sort of clinical grouping; haemophiliac/recipient of blood products, ante-natal mother, patient with chest disease, patient on dialysis and so forth. These groups are suggestive of diagnosis being made in the course of clinical consultation and seem to imply that

infection might be appearing within the 'general population', which might suggest that a generalised epidemic had taken hold. Third, there are groups reflecting the idea that the threat of HIV was one that was external to the state, thus foreign students and others, foreign going Indians and other Eastern states. However, as was said above, the data given in this document is too limited for any conclusions to be made about the nature of the epidemic in West Bengal.

5.3.4 Sentinel surveillance and AIDS case reporting

The first round of sentinel surveillance was carried out in 1998. Unfortunately, far from clarifying the situation as regards the extent of the epidemic, the sentinel surveillance seemed to increase confusion. Criticisms were levelled at the methodology used for gathering the data. This was recognised by NACO and also by WHO (interview data). For example it was argued that there were too few testing sites, a lack of rural coverage and a bias towards people using government facilities. A representative from the State AIDS Society who was interviewed in 2001 emphasised that the results of the third round of sentinel surveillance released by NACO were not to be relied upon. The following passage, taken from a document produced by the SAS is indicative of this confusion:

The development of sentinel surveillance for tracking progression of HIV epidemic in West Bengal has provided useful results. *This includes reliable information on data and trends of infection but due to limited number of sites adequate data was not available* and there is no rural representation...It is hoped that by expansion of surveillance sites and improvement of quality assurance *more accurate and reliable data* will be available to determine the current state of the AIDS epidemic in various zones of West Bengal and also to monitor trends. (Ojha 1999: 18) [stress added].

Because AIDS was not a notifiable disease and there were no formal means for the reporting of AIDS cases or deaths attributed to AIDS, the data concerning this was also unreliable. Those cases reported to the authorities probably reflected patients

who had access to the larger public hospitals where a diagnosis was more likely to be made. At the time of the study an official source stated that 271 people had been diagnosed as having AIDS within the state, although it was also acknowledged that this figure was too low (Ojha 1999: 3). A number of doctors in the study reported that they had patients who were presenting with AIDS defining illnesses, and that when tested, their spouses and children were also HIV positive, indicating a disseminated epidemic.

5.3.5 Discussion

Given the uncertain nature of the data it is very difficult to paint an accurate picture of the epidemic in West Bengal during the period under discussion. A view often repeated during interviews with policy makers and state level officials was that rates of infection were genuinely low. The director of the SAS offered a number of reasons for this. First he suggested that absolute poverty was very low in West Bengal and correspondingly there was very little malnutrition. Second, he noted that rates of sexually transmitted infections were low, there was little injecting drug use and that 'promiscuity and intermixing [were] much less' than in the rest of India. Third, the state had intervened early on to contain the epidemic. The idea that West Bengal has a more conservative and moral culture and that this had prevented HIV from spreading was stated by a number of respondents. Thus one of the tropes in circulation about HIV in India, that it was 'un-Indian', was distilled still further at the state level with HIV being seen as 'un-Bengali'. That this understanding of HIV/AIDS in West Bengal was in general circulation was evident when I was doing my field research, where a number of respondents at the national level discussed West Bengal's low rates of infection and the reason for them. As Jain et al comment

however, the view that West Bengal was essentially different in some way from the rest of India was not universally accepted:

...we do not believe that there are any specific socio-cultural, behavioural, or ethnic factors to inhibit the spread of HIV in either Delhi or Calcutta (Jain et al, 94: S66).

Irrespective of whether this belief was grounded in truth or not, it had implications for the manner in which the epidemic was understood and the ways in which a sense of ownership was created. Constructing an 'un-Bengali' slant to the epidemic would have been of little consequence if the idea of a Bengali identity lacked resonance with the general population. However, there is clearly a very strong sense of what it is to be Bengali founded upon the unifying symbols of language, a rich cultural heritage of music, poetry and literature, and a shared history including that of being partitioned, not once but twice, by the British (Judd 2004). Jalal (1995) notes that, in West Bengal class, linguistic and regional loyalties have a stronger hold than caste. Today, while Delhi remains the political capital of India, Calcutta is still frequently described as the cultural capital of India (Panda 2001).

5.4 The evolution of HIV/AIDS policy in West Bengal

5.4.1 Introduction

Initially HIV/AIDS related activities in West Bengal were developed by the State Health Department with a State Programme Officer taking the lead. Subsequently the Medium Term Plan, designed at the national level, was introduced into West Bengal in April 1991 with the support of the WHO and the Government of India. The focus of this was on blood safety and this continued with the inception of NACPI in the following year (Ojha 1999: 5). During this time-period there was very

little movement at the state level towards developing interventions with risk groups or providing support for NGOs working in this area.

Detailed information concerning the extent of NGO activities within the state at the time of the study was hard to find. Nor was it possible to establish what percentage of risk groups had been covered by targeted interventions by the close of NACPI. Approximately 25 NGOs in total were involved in various AIDS awareness and intervention programmes during NACPI (interview SAS). In addition to targeted interventions these included providing education for the police, awareness programmes in schools supported by UNICEF and the establishment of three telephone counselling services, two in Calcutta and one in Siliguri/Darjeeling. NGOs were also involved in mass media campaigns to try and raise awareness in the general population during NACPI and they participated in the Family Health and Awareness campaigns.

Unfortunately, West Bengal was among the states that failed to establish an Empowered Committee during NACPI. Interactions between NGOs and the State AIDS Cell were limited for much of this time with the inevitable consequence that there was no state level backing or support for the development of targeted interventions. In 1995, in response to this situation, the UK Overseas Development Administration via the British Council established the West Bengal Sexual Health Project (WBSHP). This represented a significant milestone in the development of HIV and AIDS related activities in West Bengal as it predated the development of a functioning SAC. This lack of engagement between the SAS and NGOs was summed up during the course of an interview with a leading functionary in the SAS who, when asked about NGO involvement, said that this was not the provenance of

the SAS and that DFID and the WBSHP were 'responsible' for targeted interventions.

5.4.2 Governance and NGO/state relationships

Against this background, it is important to understand issues of governance and NGO relationships with the government in West Bengal. It was suggested in section 5.2.2. that this might be a problematic area. A number of respondents suggested that the state was opposed to NGOs on ideological grounds. A significant impediment to the development of a role for NGOs was the reluctance of the state to work with them. Although a sophisticated party machinery existed at all levels that could have been used to promote HIV/AIDS policies, there was no political will to do so (interview data). There were also no obvious political leaders during NACPI willing to take on the issue. Key individuals in the State AIDS Cell/State AIDS Society were also reputedly very hostile to the idea of working with NGOs and resisted doing so in any meaningful way. Another significant problem was that there was no one at Panchyati Raj level who could link HIV/AIDS policy to Primary Health Centres and such like. Thus at all levels there were impediments to successful implementation of policy.

A related issue was the difficulty encountered by NGOs during this period when they tried to develop services that, by necessity, ran contrary to the law or to a perceived reading of the law. A number of respondents noted that they had been effectively blocked from developing services because they ran contrary to the legal context within India, and that there was no state level advocacy to support their interventions. Certainly the WBSHP as a bilateral project had to be careful about not being seen to advocate practices that broke the law (interview data).

The absence of tangible support at a high-enough level to alleviate concerns associated with the legality of working with men who have sex with men, injecting drug users and prisoners was raised by a number of study respondents. It became clear during the course of fieldwork that, while all the risk groups were stigmatised, some were more stigmatised than others. One respondent made the point that whilst sex workers were stigmatised they were none the less, less stigmatised than men who have sex with men, who because of their invisibility, were deemed in policy circles not to exist at all in West Bengal. This suggests that it may have been helpful to have adopted different approaches to the type of interventions developed, and the advocacy surrounding them. For example, prison inmates were essentially inaccessible to NGOs but were able to access prison medical services, suggesting that this might have been a good entry point for HIV related services and support. This issue will be discussed further in the following chapter.

It is also important to draw a distinction between state-level policies and politicians and the state level bureaucracy from which the SAS was comprised. As was discussed in chapter three, the health policy process doesn't conform to a top-down linear model and the role of individual actors at different stages in the policy process can be critical in the manner in which policies are understood and implemented (Walt 1994, Walt & Gilson 1994). It has been suggested that within India there has been a general tendency at the state level for the bureaucracy to impede the work of NGOs (Sen 1999). There were points during my research when it was evident that there was a need to better understand the fluid nature of human relationships that existed between these different structures and the individuals working within them and that it was possible for NGOs (or individuals within them) to have relationships

with state level politicians whilst having poor or non-existent relationships with employees of the State AIDS Society.

One of the NGOs raised the problem of hostility from some members of the SAS. These members were reputedly extremely hostile to any kind of NGO involvement. When asked in general terms about this NGO, a SAS respondent said that the SAS wanted nothing to do with this particular NGO and that in her opinion, it should be completely ignored. Ironically, this NGO was working on HIV awareness amongst tea-plantation workers in the north of the state and was doing so at the behest of the state government and not the SAS. Their work pre-dated the formation of the SAS and the NGO had been involved in the sensitisation of politicians earlier in the decade suggesting some sort of parallel state/NGO connections.

Unfortunately this respondent was unwilling to discuss this issue with me further. However it does raise the point that it was entirely possible, that longstanding NGOs might have developed relationships and connections with state level actors, that significantly pre-dated the emergence of the SAS. This is not to suggest that the SAS and the state government did not share the same view of HIV/AIDS in West Bengal and the appropriate policy response. However, there were nonetheless points of tension and contradiction where individual relationships were the key to understanding the success or failure of implementation.

The change of State Minister in 2000 needs also to be recognised as having had an effect on the implementation of policy. This change was accompanied by a change of Health Minister and also coincided with the start-of phase of NACP2. Respondents working with men who have sex with men noted that the new Health Minister was much more supportive of the need to develop services for men who have sex with men than his predecessor had been. For example I was told of a

meeting where both the Health Minister and the director of the SAS were present. The Health Minister was significantly more engaged with the issues raised than the latter, who had to be told by the minister to remain after the meeting to start working on the issues raised. Shortly after this a new director for the SAS was announced. Both of these examples highlight the need to be responsive to the role of individual actors and the possibility that NGOs can and do develop strategic alliances and relationships that cut across organizational lines.

5.4.3 NGOs and the National AIDS Control Programme 2

The State-led response to HIV in West Bengal was in fact very limited for most of the 1990s particularly with respect to working with NGOs. It was only during the prolonged period at the end of NACPI, when a more collaborative stance was taken at the National level with the stipulation of the creation of individual state level project implementation plans, that a renewed rigour was applied to the problem in West Bengal. Arguably, even at this point the response was tokenistic. For example a number of research participants complained of either, being excluded from the evaluation process or, of being restricted in their participation because the parameters of the debate were mapped out before they were consulted. This meant that there was no opportunity to raise areas not already included for discussion.

A document produced by the SAS in 1999 describes the status of the pandemic in West Bengal, the interventions of the SAS and the new approach to be taken to HIV/AIDS prevention and control in NACP2. Echoing concerns voiced at the national level about the extent of the pandemic, the necessity for immediate action is clearly articulated:

... infection is spreading at an alarming fast pace and there is a need to widen our response to the HIV infection...The government of West

Bengal is fully committed for [sic] preventing a catastrophic epidemic...(Ojha 1999: 15).

Thus, by December 2000 the State AIDS Cell had handed over to the State AIDS Society. A new focus of developing targeted interventions with risk groups was on the agenda necessitating working collaboratively with NGOs for the first time. A number of changes at the state level had implications for NGOs working on HIV/AIDS. The establishment of a State AIDS Society involved the inclusion of some NGOs on the steering committee. An NGO adviser was appointed with the aim of gearing up interventions with designated risk groups and there seemed to be a growing willingness at the state level to include NGOs in the response (Ojha 1999). By December 2001, in addition to the NGOs working on targeted interventions under the auspices of the WBSHP, a further 17 had been identified by the state and were in the process of starting work.

5.5.4 The West Bengal Sexual Health Project

5.4.4.1 Introduction

The West Bengal Sexual Health Project played a significant part in the design and implementation of HIV/AIDS related policies in West Bengal during the time-frame of the study. The particular model for targeted interventions that it advocated gained wide recognition amongst NGOs working on HIV/AIDS and amongst other policy makers both within and outside of the state. Despite the fact that the project was disbanded in 2001 its influence was still visible in the ongoing work of the NGOs for which it provided funding and technical assistance. As such the particular discourse of HIV/AIDS that informed the work of the project survived the project itself.

It was notable during the course of the field study that respondents across a range of settings referred to the project when discussing their own work. At times there seemed to be an overriding preoccupation with the rights and wrongs of the WBSHP

model. While this is to be expected amongst NGOs receiving funding and technical support from the project, NGOs not actively involved with it, also referred to its model for targeted interventions. For these NGOs and other actors the primacy given to this model was at times a cause of both bewilderment and frustration. Many of the NGOs in the study explicitly located their own orientation and approach to HIV/AIDS related interventions in relation to the WBSHP. Thus while opinions of the WBSHP varied from extremely positive to highly critical it was apparent that the project and the discourse that it produced served as one of the reference points for other actors in the policy process. Therefore the discourse produced by WBSHP was woven into the meanings that were attached to HIV/AIDS in West Bengal at the time of the study.

5.4.4.2 Aims of the Project

The British Council established the WBSHP in 1995 at the behest of the UK Overseas Development Administration. Although the life-span of the project was initially intended to be four years it continued for an additional two years. This was possible because of under-spending. Problems in handing over to the SAS also prolonged its life. The project drew to a close in March 2001 when its activities were handed over to the SAS although it maintained its office premises until October 2001. The project's mandate was to support the government of West Bengal in the prevention and control of STD/HIV/AIDS with a particular focus on providing targeted interventions for high risk groups. As was noted above one interpretation of this within the SAS was that the WBSHP was solely responsible for targeted interventions at the state level.

The WBSHP worked with NGOs and provided them with financial support and technical advice. At the same time it sought to raise awareness of HIV/AIDS

amongst key individuals and organizations involved in the policy process particularly, although not exclusively, at the state level. This included a certain amount of advocacy. Thus it provided a nexus between the NGO community and broader state structures that had the power to advance or impede the work of the NGOs involved in the project. A member of the SAC, and latterly the SAS, was director of the Steering Committee. This was in keeping with broader DfID policy of working with governments in the development of their programmes. It also ensured that the Government of West Bengal and the SAC were fully aware and informed of the approaches and interventions being undertaken.

5.4.4.3 Overview of the approach

The WBSHP approach to targeted interventions consisted of three key strategies. These were the syndromic diagnosis and treatment of sexually transmitted infections, the social marketing of condoms and the promotion of Behaviour Change Communication¹⁷. These were key approaches to prevention advocated in global guidelines for best practice at the time and are based upon biomedical and behavioural understandings of HIV/AIDS prevention. Thus NGOs working with the WBSHP represented the final stage in translating these guidelines within India. The term translation is used here to mean 'The process by which policies transferred from one context to another, are made meaningful and relevant to the new context' (Porter et al 2004: 86). One challenge, for both the WBSHP and its partner NGOs, in translating these approaches at the local level, was to create an environment whereby these biomedical and behavioural interventions could be reconciled with the structural factors contributing to risk and vulnerability.

¹⁷ The following definition of BCC was used by WBSHP 'Behaviour Change Communication uses multiple channels to transmit and reinforce messages that address well defined target audiences; gives people the skills and tools required to prevent HIV, and creates a supportive environment that helps people adopt and maintain safer sexual behaviour (WBSHP 1999e: 7).

The principal response to this challenge was the inclusion of a fourth strategy, the creation of an enabling environment. This required NGO's to establish a supportive environment so that interventions were acceptable to, and accepted by, the communities within which they were working. This involved identifying, and including, both primary and secondary stakeholders. This strategy also emphasised the importance of empowering project users (WBSHP 1999a and interview data). Within this framework NGOs were supported through the process of identifying secondary stakeholders who needed to be supportive of projects if they were to be able to function, the police, pimps and local hoodlums for example.

This approach to creating an enabling environment has however potential drawbacks. First, there is a risk that NGOs with an activist agenda, who decide to work on HIV prevention, might be prevented from adopting a proactive stance towards discriminatory practices within their communities, for fear of destabilising the context within which prevention activities are situated. The empowerment model upon which this approach was based, was likely to be unpopular at the state level in West Bengal. NGO activities based upon service provision have been much more readily accepted by the state than those based on an empowerment model (Sen 1999). Second, a study carried out on behalf of WBSHP of four partner organizations raised concerns that some projects were failing to draw a suitable distinction between primary stake holders, the target population and peer educators for example, and secondary state holders such as pimps, madams and brother owners. The report highlighted that many sex workers had extremely poor living conditions and that some of the secondary stakeholders were implicated in this through exploitative practices. As such their aims and interests differed significantly, with the former hoping to challenge the status quo and the latter intent upon

maintaining it. Thus it was a matter for concern that they be treated as equal partners (Gonzales et al 1999: 13).

In reality, the extent to which the NGOs in the study adopted an activist approach to their work varied tremendously. One NGO, SHIP, became highly politicised and campaigned very publicly for the legalisation of sex work. As a consequence, SHIP obtained official approval for the creation of a sex workers' cooperative. The success of this project was such that it has been used as evidence that rather than the empowerment of project workers being a necessary precondition for success, it can, in reality, come about as the consequence of a project (Gonzales et al 1999). This NGO and its approach to HIV prevention is discussed in chapter 6. Other NGOs working with sex workers however complained that this had not in any way improved the material living conditions of sex workers' lives and that the abuses that they suffered had continued unchanged despite their seeming new found status and empowerment.

5.5.1 Developing themes

Thus far this chapter has looked at a number of related issues including different understandings of the HIV/AIDS epidemic in West Bengal, the evolution of a policy response with a particular focus upon the role designed for NGOs and the relationships between NGOs, the state, and other policy actors. I want to explore a number of related themes here. The first of these concerns the hand over of the West Bengal Sexual Health Project to the State AIDS Society. What can it tell us about the translation of HIV/AIDS policy from global guidelines to the local level with respect to power and decision making within the policy process? The second concerns Hilhorst's (2003) conceptualisation of the term 'Non-Governmental Organization' as a 'claim bearing label', one that claims to do good for others, and

whether such an understanding (clearly advanced in global guidelines and national policies) was reflected in understandings at the state level. The final theme introduces the idea of NGOs as fragmented sites rather than bounded entities (Mageli 2005). This will provide an opportunity to explore further the inter-organizational relationships between NGOs involved in the study and other organizations and individuals.

5.5.2.1 Handing over the WBSHP and relationships between actors

The handover of projects from the WBSHP to the SAS makes an interesting case study because it highlights areas of tension, resistance and conflict between a number of actors at the state, national and international levels. As the time period for the WBSHP was drawing to a close, plans were developed for handing over the partner NGOs to the SAS. The initial timetable for the handover proposed that the SAS would assume responsibility for disbursement of funding and the provision of technical support and monitoring from December 2000. A new funding mechanism was required for this to take place. Although DfID was continuing to finance targeted interventions, it was proposed that, from April 2001, funding from DfID would be re-routed through NACO to the SAS. However the mechanism for this was still under discussion in December 2000 and it seemed possible at that point that NACO might have to tide over the gap to prevent NGOs going without funding. It was evident during the first period of fieldwork for this study (August – December 2000) that problems associated with the handover were emerging and that it was already delayed. The second phase of fieldwork (September- November 2001) provided the opportunity to re-interview respondents to see how things had worked out, whether anticipated problems had arisen and if so how they had been resolved.

5.5.2. The handover

A number of reasons were given for why this handover was needed. First, it was consistent with both the national and state level reorganisations of HIV/AIDS policy. The focus that NACP2 placed on the establishment of a SAS and targeted interventions made it imperative that the two be linked. Second, there were concerns that if the WBSHP continued the SAS would never take over the mantle of running and coordinating NGO activities. Third, it was also suggested that the SAS was reluctant to work with NGOs and that the existence of the WBSHP allowed them to neglect this important aspect of policy development.

This decision also reflected issues related to DfID's HIV/AIDS portfolio in India and changing priorities within DfID at the UK level. The WBSHP was an NGO project and it developed at the same time that DfID started working on two other related projects Healthy Highways and Partnerships for Sexual Health. An essential tension associated with these projects, was that they developed as a response to an urgent and immediate need and consequently by the late 1990s DfID had three projects, doing different things, with different funding and management structures, all relating to HIV/AIDS in India. However, DfID's priorities had changed to issues around governance and systems management. The WBSHP started working before a unitary system was in place, as did the other projects, therefore they were inconsistent with the new approach. By 1998, it was decided that this was untenable. After a period of consultation it was decided, at the international level, to disband the project (interview data). Thus a significant change in HIV programming in West Bengal was decided at the international level.

During the handover period NGOs experienced problems with funding that reflected differences in approaches to funding between the WBSHP and NACO. Whilst, for

example, the WBSHP paid increments to peer educators, NACO did not. The budget for the treatment of sexually transmitted diseases was also withdrawn in line with NACO policy on mainstreaming this service, as was the funding for general ailments. The WBSHP had allocated 30% of the drug budget for this and the loss of this funding was a very unpopular move amongst NGOs. It was argued both at the NGO level and within the WBSHP that the ability to treat general ailments had been a significant factor in the success of the projects because this was seem to be a ways of responding to the felt needs of project users.

Negotiations took place between NACO, the SAS and the WBSHP in an attempt to resolve these issues. NACO said that the SAS could use discretion. The SAS said that it would not act unless it had this in writing. NACO would not put it in writing. Therefore stalemate was reached. As a form of protest a small number of NGOs decided to refuse NACO funding, and one of these, was reported to be unable to pay salaries at the time of the second field trip for this study. On a field visit to this project, during this phase, project officials maintained an upbeat front stressing that they were entirely self-funding, because the project was so well liked by the sex workers who used it. However, at the end of the visit an attempt was made to obtain a 'donation' of several hundred rupees using considerable duress.

These problems cast a harsh light upon the so-called 'partnership' of NGOs in the process of developing interventions. In the face of intransigence by the state and national level agencies, NGOs were powerless to prevent core services being stripped from their projects, services that they had previously been told they had to offer if they were to get any funding at all. The emphasis upon meeting the felt needs of project users, was not enough to ensure the continuation of funding for the general health budget once the projects were up and running. This is a telling

example of the manner in which NGO activities are vulnerable if donor priorities change.

It was also reported, from outside of the SAS, that the SAS thought that the NGOs were 'babied' by WBSHP, that they did not think for themselves and were a waste of money, and that after the hand-over some of these NGOs would fail. Another view was that the SAS wanted to show the NGO community where the power lay right from the outset. Thus, the end of the second period of field research coincided with a new (but uncertain) future for the NGOs that took part in the study. This process has been described in detail because it illustrates the complexity of policy making at the state and national levels and the manner in which power was implicated in the policy process.

5.5.3 Contested Meanings

Given the tensions highlighted above, I want to look now at Hilhorst's proposition that the term 'Non-Governmental Organization' is a claim-bearing label. As such it stakes the claim of being an organization that does good for others. This assertion was challenged at the national level with NGOs implicated in post-colonial and neo-colonial readings of the pandemic (see section 4.3.5). NGO can also be seen to be a contested term within the context of West Bengal. Clearly the state itself, both with respect to government and bureaucracy has been reluctant to work with NGOs on HIV/AIDS programming. This is in part an ideological issue. It may also reflect a reluctance to support and promote interventions that challenge established power bases and promote empowerment in marginalized groups. Sen (1990) has highlighted the fact that in Calcutta [sic] empowerment as an approach is disliked and questioned and NGOs are therefore more likely to have a welfare or modernization orientation.

The issue of NGO financing needs to be understood in this context. Whilst there are many reasons why NGOs experience funding difficulties (Feeney 1998, Smillee & Helmich 1999) there are some particular circumstances in India that clearly speak of the tension between NGOs and the state. The role of foreign NGOs in financing their 'partner' NGOs in India is a matter of suspicion and one for which state regulation and control has been developed. The Foreign Contributions Regulation Act was established following a scandal in the 1970s, when it was discovered that an umbrella organization, funding Indian NGOs, was being financed by the CIA. This led to many foreign NGOs being expelled. There remains a significant mistrust of foreign funded NGOs in India (Sen 1999). In order to receive funding from overseas, NGOs have to gain registration under the Foreign Contributions Regulation Act and this enables the state to exert a considerable level of control over the types of NGOs receiving funds, and the kinds of work they can receive funding for. The ability to revoke this registration is a significant lever for the State and inevitably has an effect upon the power relationships that lie at the heart of inter-sectoral collaboration. Also NGOs must have operational for three years before being eligible for FCRA registration.

Further, the perception that NGOs are corrupt is widely held. The WBSHP placed considerable emphasis upon financial accountability. This was considered to be an important feature of project management. A respondent from the WBSHP was at pains to stress that, the rigour attached to financial accounting, arose from the awareness that many smaller or inexperienced NGOs might not have adequate experience in this area. The guiding principle was not one of creating systems to prevent corruption - rather to inculcate an appreciation of the need for accountability both upwards to donors and downwards to project users. This shows that the

perception of NGOs, as corrupt organizations, was widely held. Concerns were also voiced, at the national level, about the wrong sort of NGOs jumping on the AIDS bandwagon. Some NGOs with no experience of working with targeted groups were attracted by the promise of large tracts of funding and international exposure (Chatterjee & Sahgal 2002).

5.5.4 NGO- a fragmented site

This chapter has looked in some detail at the interrelationships between the NGOs in the study, and other actors and organizations, and has considered the implications of these relations for the translation of policies from the international and national levels. For NGOs with their extensive role, the ability to work collaboratively with other actors in the policy process and build strategic alliances is crucial (De Jong 2003). Thus in order to understand NGOs it is necessary to understand their relationship to wider political and social structures and the interconnection of NGOs with their communities and broader state structures [Hilhorst 2003, Mageli 2005]. Given these multiple relationships and the evolving context within which they work, Mageli argues that it is more useful to consider NGOs as ‘...fluid entities, consisting of fragments rather than a fixed core...actors entangled in a web of relationships...’ (Mageli 2005: 253).

As such the relationships within and between NGOs and other organizations, institutions and individuals can be understood to have shifting boundaries. Rather than understanding NGOs as distinct bounded wholes they can be seen as sites of changing activity, where people form relationships and alliances, support and overlap with other organizations and break away to form new alliances and coalitions. This was evident in the way in which respondents in the study moved from one job to another, when a project reached the end of its funding, often

changing to a new organization, taking organizational knowledge with them. There were also clear alliances around key issues, such as approaches taken to the legalization of sex work. Other NGOs working with a particular group, street children for example, shared a common platform through participation in Kolkata's City Level Plan of Action for Street Children.

During the life time of the WBSHP, NGOs were encouraged to develop a network, the NGO AIDS Coalition, where experiences could be shared. The aim of this was for NGOs to develop their own forum for identifying and responding to common problems and experiences. It was intended to provide a platform from which they could engage with the broader policy issues affecting them. During the first phase of field-work, none of the NGOs mentioned the network when asked about co-operation, inter NGO working and collaboration. When directly asked about it, the most common response was that it had been useful earlier on but was no longer necessary. It was also suggested that it had been 'taken over' by one of the larger NGOs as its own platform and that this co-option had caused resentment. It was also suggested that it was a waste of time. Ironically, during the second phase when problems with the hand-over to the SAS began to emerge the network did regroup. This suggests that while on a day-to-day basis the NGOs were possibly unwilling to share too much information, seeing other NGOs as a potential threat, they were able to unite when a tangible threat to their future emerged. Arguably this is indicative of the insecurity that lay at the heart of some of the NGOs in the study making the necessary collaboration unlikely. In this climate, ties of kinship and caste and traditional relationships of patronage may be the necessary precursors for inter-sectoral working.

5.6 Concluding comments

West Bengal was identified as a potential High Risk State early on in the epidemic. Kolkata was one of the first five cities earmarked for an intervention as part of the medium term plan drawn up by the Government of India in conjunction with the WHO in 1989 (NACO 1999). Despite this, for much of the time frame of the study the policy response was limited. While significant efforts were expended to draw up and implement a policy for blood safety, there was little movement on developing knowledge about the contours of the pandemic in West Bengal. Testing for HIV was largely coercive and focused on foreign students, sex workers and latterly truck drivers. These data were collected unsystematically and were of limited use as the basis for prevention and control interventions, their primary purpose was to confirm what was already 'known' about HIV/AIDS and the types of people at risk of contracting it.

Rather than clarifying the situation, the introduction of sentinel surveillance added to the confusion about what type of epidemic (if any) was taking hold within the state. While some argued that there was not a problem others, for example some doctors, argued that they were seeing whole families who were HIV positive and this was indicative of a generalised epidemic. This study was not designed as an epidemiological study and the issue at stake here is not which of these two positions was the correct one but rather to consider what the implications were for the development of pro-active prevention and control strategies.

In the previous chapter it was suggested that HIV/AIDS had been constructed as being an un-Indian disease and that this had had significant ramifications for the development of policy. During the course of this study it was evident that this belief had been distilled still further so that HIV/AIDS was believed by many to be un-

Bengali, that Bengalis were literally more moral, and therefore not at risk from infection. Further, as one respondent put it, 'mixing was much less' in West Bengal, suggesting that this was not simply a matter of sexual interactions between people but more broadly about social mixing between and across communities. Jalal's observation that class, linguistic and regional ties are relatively stronger than those of caste in West Bengal is worth considering with regards to this (Jalal 2005). It also raises the question of how to create a sense of ownership of the problem, a necessary precursor for effective prevention and control and care and support strategies.

Given then, that the nature and extent of HIV/AIDS in West Bengal were contested throughout the time frame of the study, it is perhaps not surprising that the policy response was slow. The association of HIV infection with foreigners, sex workers and truck drivers, all of whom could be broadly constructed as 'outsiders' either with respect to national and regional identity or with respect to deviancy, may well have impacted upon the State's willingness to develop prevention and control activities. However, there is another issue at stake here and this concerns the willingness of state level functionaries, for example those in the State AIDS Cell, to adopt and promote interventions where NGOs take a primary role. It is problematic to state unequivocally, that political ideology was the defining factor that undermined NGO/State relations during NACPI, but it needs to be recognised as a significant contributory factor. This goes some way to explaining why there was such limited engagement with NGOs during this period. Given these limitations, the intervention of the WBSHP can be seen as timely and important. The project was responsible for a significant amount of the training and financing of NGOs within the state and played a crucial role in the development of targeted interventions. However, as is often the case in donor-funded projects, the time frame of the project

was limited. Inevitably the question of NGO/State relationships was high on the agenda again at the end of the time frame of this study. Against this background the next chapter will look at the role of NGOs in identifying risk groups and developing targeted interventions.

Chapter 6

Competing Discourses in HIV Prevention and Control: NGOs and HIV/AIDS Programming in West Bengal.

6.1 Introduction

In recent years, a significant role has emerged for NGOs in HIV/AIDS programming. The literature suggests that NGOs are in a unique position to respond to the AIDS pandemic. Reasons for this include their perceived ability to reach individuals and groups marginalized by society, thus ensuring access to otherwise vulnerable and hard-to-reach individuals. They are also said to provide a safety net for those who are unable or unwilling to avail themselves of public or private health care and related services. Because NGOs arise from within these communities or have established a close working relationship with the communities they are better able to identify the particular determinants of vulnerability and work in partnership to find solutions to them (Mercer et al 1991, Asthana & Oostvogels 1996, Gellert 1996, World Bank 2003). Moreover their reputation for activism suggests that they will be well equipped to promote a human rights based approach to the pandemic (United Nations 1996).

During the timeframe of this study, the approach to HIV/AIDS prevention and control in India, promoted within national level policies, was that of targeted interventions aimed at high risk group. It was anticipated that NGOs would identify groups at risk of infection, within their communities, and develop appropriate interventions (NACO 1999, NACO 2000). In view of this policy orientation, this chapter is concerned with the different ways in which NGOs working at the local level in West Bengal, understood the problem of HIV/AIDS and the responses that

they developed in light of these understandings. Section 6.2 explores how risk groups or vulnerable groups were identified by the NGOs in the study. Section 6.3 examines the tensions and contradictions that existed between working with risk groups and attempts to promote a human rights based approach to HIV/AIDS programming. Section 6.4 explores competing discourses within NGOs working with commercial sex workers and how these were reflected in their approaches to prevention and control. It takes as an example, two different ways in which the 'problem' of commercial sex work was constructed, and the solutions to the problem arising from these constructions. This illustrates the fact that NGOs working on HIV/AIDS did not represent an homogeneous whole and in some circumstances had conflictual, rather than cooperative, relationships one with another. Finally, section 6.5 considers the extent to which NGOs in the study were able to respond to felt need and highlights the importance of NGOs being able to contribute to the wider policy debate about HIV/AIDS policy and programming.

6.2 Discourses of Risk and Vulnerability

6.2.1 Techniques for Identifying Risk Groups

One question posed by the study was that of how the risk groups had been designated, given the lack of reliable epidemiological data (see section 5.3). Of interest were the methods used for identifying and demarcating the groups and the underlying rationale for choosing particular groups in the first place. The techniques and methods used to identify risk groups, and understandings about the underlying causes of their vulnerability, varied considerably from project to project. For example there was a significant theoretical gap between the quantitative approach adopted by partner NGOs of West Bengal Sexual Health Project, and the methods

adopted by some of the other NGOs in the study. This difference was also reflected in the way in which they chose to work on HIV/AIDS prevention.

The projects funded by WBSHP had all undergone a formal application process initiated in the first instance by the NGO. The steering committee of the WBSHP then established whether or not the NGO fulfilled certain criteria, for example that it was organizationally sound and eligible for F.C.R.A registration¹⁸. The NGO with support from WBSHP then carried out a needs assessment. This included identifying high risk behaviours, mapping locations, identifying secondary stakeholders and so forth. The WBSHP provided guidance and training for this (WBSHP 1999a). It nonetheless required a degree of technical and managerial competence on the part of the NGO and the availability of a cadre of volunteers willing and able to implement the assessment. This was undoubtedly a challenge for some of the NGOs.

Another cluster of NGOs had identified risk and vulnerability through a process of befriending or getting to know marginal groups. They had done by sitting and talking to people over a period of months and, in some cases, years. This was particularly evident in some of the NGOs working with commercial sex workers and their children, street children and drug users, where a high degree of trust was seen as necessary before any sort of intervention, whether it be HIV related or not, was offered. HIV was thus one potential problem within a constellation of other problems.

For a small number of NGOs, their work was actually initiated by an outside agency rather than arising organically. The project that developed into the Sexual Health Intervention Project (SHIP) arose out of an epidemiological study into rates of infection amongst sex workers within the Sonagachhi Red Light District. This study

¹⁸ See page 184 for a discussion of the development of the FCRA and its regulatory function.

was initiated by the World Health Organization (WHO) in conjunction with the All India Institute of Public Health (AIIPH) (Jana & Banerjee 1999). A second NGO was working with tea-pickers in the tea plantations of Darjeeling at the behest of the Government of West Bengal. While the WBSHP stipulated that NGOs must in the first instance approach them, it seems that towards the end of the timeframe for the project, they were more proactive in trying to establish an intervention for men who have sex with men. One respondent working in this area said that the NGO was initially approached by the WBSHP and asked to carry out a needs assessment because there was an urgent need for the development of services within the state and nothing had materialised to date.

6.2.3 An Emerging Discourse

While the above discussion offers some indication of the operational factors involved in identifying risk groups, of primary interest was the underlying impetus for, looking for, risk and vulnerability within any particular community or group in the first place. What had led some groups to be identified as high risk and not others? Eleven NGOs participated in the study and between them they had identified a total of twelve risk groups. Of these, sex workers featured most prominently, as would be expected from the orientation of NACO policies (NACO 1999; NACO 2000). A number of the NGOs were running projects based in Red Light Districts throughout West Bengal working with brothel-based sex workers. Other projects were targeting floating-sex workers, flat-based sex workers and high-class call girls. A number of the other risk groups also reflected NACO target groups namely truck drivers, street children, injecting drug users and men who have sex with men. Thus, inevitably, for NGOs the identification of these risk groups was the embodiment of their engagement with wider prevailing discourses around HIV.

What was less clear in the initial stages of the study was how some of the other groups had been identified as being at risk. These groups included prawn fishermen and women, railway porters, rickshaw pullers, vegetable sellers, gold workers, jute-mill workers and tea plantation workers. What was it about people thus employed that marked them out from members of the general public? A member of the Project Management Unit (PMU) of WBSHP was asked specifically about the factors that contributed to prawn fisherwomen being categorised as a risk group. The reply to this question was that it was essentially a physiological problem. Prawn fisherwomen were immersed in salty water for long periods of time and this made them more susceptible to catching sexually transmitted infections including HIV.

As the study progressed, it became clear that the NGOs were largely focusing on groups that were poor and socially marginalized. As such, they were engaging with the high risk situation model. Poverty, gender inequalities and pre-existing stigma, leading to discrimination and human rights abuses, were consistently offered as the root causes of vulnerability and associated risky behaviour (poverty was cited as an underlying cause of vulnerability in all but one of the target groups - the exception being men who have sex with men). Other structural factors such as lack of education, lack of access to health care, and legislation that discriminates against different groups like sex workers, men who have sex with men and injecting drug users were also identified.

6.2.4 Effects of Migration

Many of the vulnerable groups, while having a distinct occupational basis, shared the overarching characteristic of drawing upon migrant or highly mobile populations. Some categories of truck drivers, for example, can spend up to eleven months of the year on the road. It was also a factor that applied to several other groups working in the informal sector, for example rickshaw pullers and station vendors. Migrant workers were also identified as a risk group in the Kolkata port area. The people thus identified, originated from rural communities within West Bengal as well as from other states, or in the case of truck drivers the neighbouring countries of Nepal and Bangladesh. The sharing of borders both with highly impoverished states and with economically disadvantaged countries contributed to the absolute number of people on the move looking for work. The impact of insecure livelihoods and rural to urban migration in search of work is well documented (Mann & Tarantola 1996, Sircar & Tewari 1996, Barnett & Whiteside 2002). The impact of prolonged periods spent away from home was cited as a significant factor affecting vulnerability. The employment opportunities for these migrant communities were extremely limited and the work was characterized as financially insecure. The need to survive from day to day was an overriding concern.

In addition to financial hardship and related stress, many of the men had come to the city looking for work leaving behind their homes and families. This led to profound feelings of loneliness. The men were said to lack any sense of belonging and lived a fractured existence, interspersing periods of living and working in the city with infrequent visits home. Furthermore, in an environment where the focus was on day-to-day survival, thoughts of a threat to health and livelihood at some point in the future, possibly years hence, was of little importance or relevance. Respondents

noted that this mobile workforce frequently relied upon temporary or inadequate housing and lacked access to schools, medical facilities and recreational outlets. Truck drivers lived in the cabs of their trucks for prolonged periods of time. In this context, respondents expressed the view that recourse to drug abuse and/or paying for sex offered a release or escape from the unpleasant realities of their daily existence. What the respondents were unable (or unwilling) to do was to comment on the broader context with regards the ability of the state or large employers to absorb this migrant workforce and provide the necessary infrastructure to meet their basic needs.

6.2.5 Occupational Basis to Groups

In practical terms the NGOs were looking for, or had identified, vulnerability amongst the communities with which they already worked or with closely associated groups. Thus it later transpired that the project working with prawn fisherwomen had been doing so for some time specifically on issues around income generation. The problems experienced by these women in their working lives, particularly with regards abuse and exploitation by powerful men in the fishing industry, led the project workers to suspect that they might be vulnerable to other forms of exploitation including sexual exploitation. A needs assessment carried out amongst the women confirmed this.

This occupational focus for many of the identified groups may also be a reflection of the manner in which some occupations are stigmatised in West Bengal/India. Whether the underlying cause of this stigma was to do with caste/jati group affiliation is impossible to say. Ramasundaram (2002) in the editorial of a British Medical Journal themed issue on HIV/AIDS makes the following observation:

India is particularly vulnerable to an explosive growth in HIV infection because of the many obstacles to HIV prevention campaigns including widespread poverty and illiteracy and *social inequalities based on caste and gender*. (Ramasundaram 2002: 182) [stress added].

Barnett and Whiteside (2002) also pick up on the issue of caste. However the implications of caste and jati group for policy development are not discussed in policies and are rarely mentioned in the literature. This absence, or silence, raises a series of interrelated questions. Is caste excluded because it lacks relevance (this does seem unlikely)? Is it deliberate, or is its exclusion an artefact of blueprint HIV/AIDS policies? Is it an example of what happens when policies are transferred wholesale from one context to another without the understanding of the cultural, social and political context? The focus upon particular migrant groups may also reflect a local engagement with an 'un-Bengali' discourse of HIV in wider circulation within the state (see section 5.3.5).

6.2.6 Power Relations

To sum up, the NGOs involved in the study were clearly engaging with a development model of vulnerability. What this meant, however, was that there was an almost exclusive poverty focus to the creation of risk groups. When NGOs did try to engage with less visible groups they ran into real difficulties which reflected power relationships between NGOs and different categories of social actors. For example one NGO working with truckers wanted to develop a project for businessmen whom they believed to be at risk. As a study participant noted however, there was no model available to guide them and they were unable to establish a means of accessing businessmen. Sircar and Tewari (1996) identify a similar problem when they cite the lack of progress in assessing risk and vulnerability amongst a number of migrant/mobile groups including salesmen and businessmen, seasonal migrants, artisans and students. Priyya (1994a) also addresses

this issue observing that innumerable other occupational groups travel in the course of their work, professionals, diplomats and executives for multinational companies, for example, yet they have not been sought out or targeted for interventions.

Another NGO was undertaking a research project on high-class call girls and had experienced significant problems in reaching the girls. These women, predominantly university graduates were working without their families' knowledge, had a wealthy client base, and were able to negotiate the terms under which they were willing to be interviewed or simply to refuse to participate. The middlemen who acted as brokers between the call girls and clients reinforced the need for absolute confidentiality. These men had a financial interest in ensuring that the client's anonymity was maintained. Interestingly, funding agencies were reportedly unwilling to finance work with this target group because the women and their clients were felt to be sufficiently educated and well informed to adopt safer sex practices. This is problematic because studies carried out in the 1990s suggested that levels of awareness were low across the board in West Bengal with educated women also exhibiting low levels of awareness (Porter 1993, Poddar et al 1996, Balk & Lahiri 1997). Low levels of awareness of HIV/AIDS in West Bengal was also raised as a problem during the course of the field work for this study (interview data UNAIDS, WBSHP).

6.2.7 Psychological factors

In addition to the structural factors identified, a number of NGOs described the emotional and psychological impact that daily discrimination and stigmatisation had upon their users (for example sex workers, truck drivers and injecting drug users) and were explicit in linking this to vulnerability to HIV, commenting that feelings of worthlessness and a sense of hopelessness about the future had a knock-on effect. One respondent, from an NGO working with a number of client groups, identified the most

prevalent problem faced by their project users, as that of insecurity and the emotional and psychological harm caused by being on the margins of society.

Respondents working with truck drivers emphasised the profound loneliness and isolation that these men experienced through spending so much time away from their homes and families, coupled with the stigmatised nature of their occupation and its association with drug and alcohol abuse, and the sex trade, which were well established prior to the HIV/AIDS epidemic. The point was repeatedly made during the course of interviews and field visits to NGOs that, in addition to the tangible physical consequences arising from inequality and stigmatisation, there were profound psychological consequences that significantly contributed to risk taking behaviour. Ironically being the target of HIV programming was felt to make this worse reinforcing the sense of social exclusion.

6.2.8 Challenging the Idea of Risk Groups

Despite the prevailing focus upon risk groups, some of the NGOs were clear that the problem was not just restricted to these groups and that it was affecting all sections of society. One such NGO that carried out a broad range of awareness activities, aimed at specific groups *and the general public* had established a support group for people infected with HIV together with their friends and families. It was clear from interviews and from meeting with the support group that their experience was that anybody was potentially at risk of infection. The repeated focusing upon risk groups to the exclusion of all others was perceived to be alarming, leaving as it did a void at the heart of prevention and control activities. It also left people, who fell outside of the risk groups, struggling to find help, support and advice if they were HIV positive or if they wanted to be tested. This NGO had been established by a group of people,

both health professionals and members of a haemophilia society who had first-hand experience of these problems.

There was a second NGO where some study participants working on targeted interventions also raised the question of how the general public were being affected by HIV. This NGO had a long history of working in social development. It had specific targeted interventions working with migrant labourers, rickshaw pullers, flat-based sex workers, injecting drug users, porters, vendors, and other floating populations at a major railway station. However it was also able to offer general healthcare and to do so to anybody who might need this service. A mobile clinic went out to various points of the city and while, for example, street children and adolescents from the railway station would be their target group on a given day, the service was also open to the general population. A discussion about this led one doctor to note that HIV was not only in the target population but also in the general population. It was notable however that few of the study respondents expressed this view.

6.2.9 Gender and Sexuality

As discussed above, a development model was used as the framing device to identify groups and to explicate the structural factors giving rise to vulnerability. While psychological factors were also acknowledged to play a role, little was said about how gender and sexuality might be implicated. This lack of discussion around the subject was marked, particularly in view of the fact that the aim of the targeted interventions was to change the sexual behaviour of members of particular targeted groups. Study respondents involved in targeted interventions were generally positive about the approach. The consensus seemed to be that if the approach was implemented rigorously enough, then safer sex amongst project users was the

inevitable outcome. This reflects the global policy response to HIV/AIDS at the time of the study. This was still predominantly founded upon biomedical and behavioural approaches to prevention.

It is however, important here for me to stress the fact that I had been given access to many of these projects in the first instance by the WBSHP. This also funded aspects of their work. As such it is possible that respondents were unwilling to be seen to be critical of their donor's approach or to suggest that the interventions might not be effective. I also became aware, over time, that respondents were discussing these interventions in relation to their perceptions about what constituted 'normal practice' in Britain. Thus I was told on several occasions that prior to the project, respondents were 'not allowed' to talk about sex, or that sex education was prohibited in India except in relation to these projects. The contrast was then drawn with what was believed to be a British approach, as opposed to the Indian approach, to discussing matters of a sexual nature. This obviously links with the dualism of the chaste Indian and the deviant west discussed in chapter 4. Whilst openly positive about the approaches that they were using, there were a few occasions when some reservations about aspects of this work were expressed. For example, I found that when visiting projects, I was often shown a flip chart, with photographs of individuals with sexually transmitted infections intended for teaching purposes. I could never think of anything to say in relation to this and finally, one day, I said that I would rather not look at it, having seen it before. The response from the project staff was clear and unanimous. It was a horrible thing that they hated, but they had been told that they must show it to people. If I did not want to see it that was good - it could be put away.

This alerted me to the fact that respondents might be waiting for cues from me to indicate what approach to take to discussing certain aspects of their work. I found these conversations really interesting because the understandings of British cultural practices were often alien to me, and I frequently tried to talk about how hugely controversial the subject of sex education for children and adolescents was, in the UK. Reflecting on these conversations, away from the field, I felt that the training and education around these interventions probably provided some respondents with information that they had not previously had access to (this was confirmed by respondents involved in training activities) and was therefore useful for them. Thus part of their enthusiasm about the targeted interventions may have related to their own subjective engagement with the knowledge that they had acquired.

6.3 Addressing the Human Rights Dimension

6.3.1 Introduction: Risk Groups, Stigma and ‘Othering’ the epidemic

The previous section looked at emerging discourses of risk and vulnerability implicated in the identification of so-called risk groups. This section is concerned with the relationship between these risk groups, the stigmatisation of group members and evidence that there has been an ‘othering’ of the pandemic. Early responses to the pandemic in India were rooted in generating fear which enabled the rest of society to assign blame and construct the epidemic as one of guilt and innocence (Priyya 1994a). The associated discrimination was legitimised through the link to public health and the reputed threat that the members of risk groups pose to the rest of society. This enabled individuals to disassociate themselves from the disease by distancing themselves from any association with risk groups (Goldin 1994). Clearly

this has implications for a policy response rooted in community action and a sharing of the problem.

The development model based on vulnerability was intended in part to get away from this process of 'othering'. However, in West Bengal at the time of the study, as throughout India, the concept of the risk group was the cornerstone of programming. These risk groups already bore the heavy burden of a stigmatising identity. Thus, HIV/AIDS had become inimically bound up with pre-existing stigmatised groups. Members of these groups were further stigmatised by their association with the AIDS pandemic (Gilmore & Somerville 1994). The process of identifying and labelling groups reiterated and reinforced the marginal status of group members. Thus the tendency to demarcate the pandemic as having its roots in poverty has simply reinforced the marginal status of poor communities and poverty has joined sexual deviancy as a potent symbol of threat to mainstream society.

6.3.2 A culture of 'no blame' and a discourse of pity

It became apparent very early in the study that the NGOs were very 'on message' with regard to the factors giving rise to vulnerability amongst their project users. Therefore the culture, ostensibly at least, could be described as one of 'no blame'. The language of deviancy was absent so that behaviours that might carry a degree of social approbation (such as alcohol and drug abuse, the buying and selling of sex) were discussed without attaching a value judgement to them. By and large, the respondents expressed considerable sympathy for the people with whom they worked, painting them as victims of an unfair and unequal society whose life choices were significantly constrained by external forces. Despite the prevailing orthodoxy within NGOs being one of sympathy for their project users, the very process of working with these groups and attaching a label to them has contributed

to the 'othering' of the epidemic. This has serious consequences both for prevention and control strategies and for the provision of care and support.

Against this background, a discourse of pity was used to 'neutralise' the damaging inscription of blame associated with being identified as at risk of infection. The word 'poor' was used frequently in interviews to describe project users. For example drug addicts were 'poor boys', truckers were 'poor men' in sensitization literature. Project workers clearly articulated the miserable and impoverished lives of project users, the despair and abuse suffered by them and their abject powerlessness to either challenge the abuse or to change the material conditions of their existence. This can be seen both as an empathetic response in the face of great suffering and a pragmatic attempt to elicit a sympathetic response from an otherwise hostile society. However, it also runs the risk of further entrenching the 'othering' of targeted groups. For example, one NGO had produced sensitization literature for the trucking industry where the truckers were portrayed as essentially promiscuous and disease ridden. This material simultaneously evoked the need for sympathy:

It is time you helped others who know least about the disease - and yet are most exposed to it. Namely your trucker friends and especially those infected amongst them. As his more fortunate colleague, you are actually in a position to become a true friend and advisor... (taken from sensitisation literature aimed at the trucking industry).

Ironically, the managers and business leaders to whom this material was addressed constitute the type of people another NGO wanted to target but were unable to access. There is no mistaking in this literature who is seen as at risk of contracting HIV and who is being asked for help to mitigate the burden of the disease. Power relations, once again, are clearly at the heart of this.

6.3.3 Negative consequences

It was evident during the fieldwork for this study that members of risk groups were experiencing damaging consequences by being so marked out. Examples offered from within NGOs included the difficulty some truck drivers were experiencing in finding a wife. It was said that in one village where working for the trucking industry was the principle occupation for young men, they were effectively shunned by neighbouring villages and unable to find wives. Respondents working with truck drivers were aware that their interventions were in some instances reinforcing the sense of alienation felt by project users.

A needs assessment carried out by an NGO working with men who have sex with men also had a negative impact upon the targeted community. The assessment led the police to a cruising area within a public park where men had been able to meet one another while 'passing' as part of the general movement of people circulating throughout the park. This led to the public toilets being bulldozed and men being harassed. The park was subsequently closed in the evenings.

There were also varying accounts given of an incident involving an NGO carrying out a needs assessment amongst a trucking community within a rural village and the impact of the final report. While accounts varied in terms of the detail it was agreed that when the NGO published its final report it caused consternation amongst the villagers, who held that it portrayed them as promiscuous and disease ridden and threatened the social networks that existed between themselves and neighbouring villages. The NGO was driven out of the village. This had become something of an apocryphal tale amongst NGOs in as much as it stood as a warning of what could go wrong. Interestingly nobody was willing to talk in any detail about the incident

although a number of respondents alluded to it suggested who should be approached for more information.

These examples convey some of the potential problems of focusing on groups. Many of the factors that enable the groups to be identified - their accessibility to NGOs, their inability to resist the scrutinizing gaze of epidemiologist, social scientist and doctor, and their vulnerability to instruments of social control and repression such as the police and misapplied judicial system - arose from their stigmatised and marginal position in society. The reverse of this was that other, more powerful individuals have proven to be inaccessible to these processes of identification and had, as such, sidestepped the stigmatising label of belonging to a risk group. This was evident from the study where respondents found it impossible to access members of certain occupational groups.

The discourse of pity also failed to engage with the fact that all people have human rights that entitle them to certain things including respect and privacy (Timberlake 1997). Instead it focused on trying to elicit sympathy for the target groups because they could not help their 'deviant' and 'immoral' behaviour. This inevitably opened a discursive space where people could still be blamed for their behaviour and for the risk they pose to others.

6.3.4 Enabling Environments and Human rights

Given the above, it is clear that certain policy responses can reinforce stigma and stereotyping (Gilmore & Somerville 1994) and that stigma and stereotyping can hinder prevention and control activities (Priyya 2008). The creation of the UNAIDS in 1996 was in part a response to the discrimination and human rights abuses

directed at those infected and affected by HIV/AIDS. Human rights are central to its mandate:

In the context of HIV/AIDS, an environment in which human rights are respected ensures that vulnerability to HIV/AIDS is reduced, those infected with and affected by HIV/AIDS live a life of dignity without discrimination and the personal and societal impact of HIV infection is alleviated. (United Nations 1996: 4.)

Moreover guideline 2 of the United Nations *HIV/AIDS and Human Rights: International Guidelines* on 'Supporting Community Partnership' clearly articulates the role to be played in this by CBOs including NGOs:

States should ensure that ...community organizations are enabled to carry out their activities, including in the fields of ethics, law and human rights... Community representation should comprise PLHAs [Persons Living With HIV/AIDS], CBOs [Community Based Organizations], ASOs [AIDS Service Organizations], human rights NGOs and representatives of vulnerable groups. (United Nations 1996: 15).

It goes on to state that community partners have knowledge and experience of human rights problems and that this knowledge and experience needs to be included in the development of HIV/AIDS policies. Further, funding should be made available for capacity building and training in HIV related ethics, human rights and law. This foregrounds human rights and the role of community based organizations in promoting them (United Nations 1996).

6.3.5 Creating an Enabling Environment

As was discussed in chapter 5 the gap between the developmental basis for identifying risk and vulnerability and the biomedical models implicated in targeted interventions was bridged, to some extent at the policy level, by the idea of creating an enabling environment. Thus the NGOs in the study working on targeted interventions under the auspices of the WBSHP were supported in identifying the secondary stakeholders within their communities who could potentially prevent the

projects from being successfully implemented. Secondary stakeholders ranged from the police and local community leaders, politicians and key players in civil society to the pimps, madams and brokers involved in the sex industry. Setting up interventions with certain occupation-based risk groups also demanded the cooperation of employers and such like. For example, the active cooperation of the trucking industry was sought in developing projects aimed at truck drivers. However many of these secondary stakeholders were identified in the study as contributing to the vulnerability of target groups in the first place, for example the police, pimps and madams.

This posed an interesting dilemma for NGOs. How could they reconcile the need to create an enabling environment as conceptualised in NACO policies with their advocacy and activist role and is it reasonable to argue that the approach undermines a human rights based approach to HIV/AIDS policy? The process of identifying secondary stakeholders was one that employed depoliticised language. Essentially, however, it was about mapping power networks and could be viewed as highly political. By placing importance on the need to placate secondary stakeholders and to assure them that targeted interventions would not undermine their power base, NGOs with an activist agenda were in effect agreeing not to pursue an empowerment agenda with broader structural ambitions.

All of the NGOs in the study identified the wide scale abuse of human rights as a significant factor affecting an individual's ability to protect him or her self from infection with HIV. Central to this issue was the question of whether by pursuing strategies aimed at creating an enabling environment, NGOs were compelled to relinquish their activities to fight local level structures and individuals, which contribute to the erosion of human rights amongst targeted groups. Gonzales et al

(1999) in their evaluation of four partner organizations of WBSHP identified the blurring of the line between peer educators and secondary stakeholders as a problem in some cases and stressed the need to ensure that secondary stakeholders not be treated in the same manner as peer educators. This study also stressed the need for advocacy against violence as a core activity.

An example of this dilemma in practice occurred when a peer educator working with an NGO was raped in a public place. This woman was said to have ‘provoked’ local hoodlums because she had refused to stop promoting safer sex amongst sex workers. They had raped her both to silence her and to send a message to the wider community of sex workers about the consequences of getting involved with the project. The NGO in question approached its funding agency asking for advice and was advised to do nothing lest they damage the ongoing delicate balance of work with secondary stakeholders. This NGO had a long history of working on human rights and was predominantly an activist organization. As such it decided to go ahead and support the sex worker in lodging a complaint with the police. Given the reputation of the police as being hostile to sex workers this was a bold move. In fact, the police took the complaint seriously. While this was an extreme case, several of the NGOs said that they were aware of the need to keep powerful factions on side, limited their ability to work on the broader structural issues affecting the lives of their project users.

6.4 Competing discourses and contested meanings

6.4.1 Introduction

So far, this chapter has explored representations of risk and vulnerability in circulation amongst NGOs working on HIV/AIDS in West Bengal. This section is

concerned with the manner in which NGOs working with sex workers drew upon competing discourses to 'explain' the problem of sex work and offer solutions. In doing so, it problematizes the issue of human rights, illustrating that consensus, even amongst actors with an implied shared identity (for example the community of non-governmental organizations working with sex workers) can be difficult to achieve. In consequence, it questions the assumption that NGOs will be able to bring about the changes necessary to uphold and maintain human rights and reinstates the state as a key player in this struggle.

The 'problem' of commercial sex work had assumed considerable prominence amongst policy makers by the time of this study, and sex workers were one of the groups identified by NACO to receive targeted interventions (NACO 1999). This can be read as the inevitable consequence of the prevailing public health discourse that strongly implicated sex workers in the spread of HIV/AIDS (Carovano 1991, De Bruyn 1992, Long 1996). Unsurprisingly, there was considerable disagreement about both problem definition and how the problem should be addressed. This was reflected in an ongoing struggle amongst the NGOs working with sex workers for the right to 'define' the problem and to gain influence with donors and policy makers. A significant factor contributing to getting the 'problem' of prostitution onto the agenda and keeping it there, was that of the success of the Durbar Mahila Samanwaya Committee (DMSC) in promoting its own work (and indeed its very existence) and actively campaigning for the decriminalisation of sex work.

6.4.2 Background to DMSC

In 1992, the All India Institute of Public Health (AIIPH) and the WHO conducted a study into rates of HIV infection amongst sex workers working in the Sonagachi Red Light District in North Calcutta. This epidemiological study developed into an

intervention project - the Sexual Health Intervention Project (SHIP) or the Sonagachi Project as it is widely known. The project had developed its own model for working on HIV prevention and control and, according to their literature the needs and interests of sex workers were given primary importance. Sex workers were given a central role in planning and designing the intervention and also shared in decision-making. (Jana et al 1998). The approach was summed up as the three Rs - Respect, Reliance and Recognition; that is '...respect towards the sex workers, reliance on them to run the programme and recognition of their professional and human rights' (Jana et al 1998: 103).

Over time, SHIP's work on HIV/AIDS prevention became part of a wider constellation of activities and services aimed at improving the material living conditions of sex workers and protecting their human rights. One striking achievement of the project has been the creation of a forum for sex workers, the Durbar Mahila Samanwaya Committee (DMSC), as distinct from the funded project. The DMSC was established in July 1995 and by 1999 had 60 branches in red light districts throughout West Bengal and claimed to represent 40,000 sex workers (female, male and trans-sexuals). The long-term aims of the DMSC are to fight for the full legal recognition of prostitution as a profession (with the creation of a self regulatory board), the decriminalization of sex work and the abolition of existing laws governing the sex trade (Jana et al 1998).

The DMSC successfully lobbied for the right to establish a co-operative society, the Usha Co-operative Multipurpose Society Limited. This cooperative society is registered under the West Bengal Co-operative Societies Act (1983). On a practical level, it provides sex workers with the facility to save money and obtain loans at reasonable rates (previously denied sex workers). Symbolically it represents a huge

step forward for sex workers because it provides state recognition of their rights as workers.

The Sonagachi model has been said to illustrate that empowerment of vulnerable groups in society can be achieved as a consequence of targeted interventions rather than being a necessary precursor to the successful implementation of targeted interventions (Gonzales et al 1999). This has implications for the manner in which projects are designed and to an extent can be seen as a justification for focusing on sexual health within an empowerment model as opposed to broad based social interventions that would be more expensive and complex to implement. Others however have questioned whether it can be replicated outside of West Bengal (interview data). The project made some significant claims for itself with regards its success in preventing the spread of HIV through consistent condom use. At the time of the study it argued that HIV rates amongst sex workers remained low at below five per cent. It also claimed that entry into the sex trade in Sonagachhi was one hundred per cent voluntary and that the trafficking of girl children for the sex trade had completely stopped. At the time of the study both of these claims were hotly contested by other NGOs working with sex workers and by some doctors, including the clinical director for virology at the school of Tropical Medicine, where much of the HIV testing was taking place at the time.

6.4.3 Strategies to raise awareness of their approach

The DMSC was extremely successful in publicising its work and keeping its demands for decriminalisation of sex work on the political agenda. It claimed to be the legitimate and rightful voice of sex workers because all of the members of the DMSC are sex workers or the children of sex workers, whereas other NGOs work with or on behalf of sex workers. This is a crucial difference. It also claimed to

represent every single sex worker in West Bengal. These pronouncements can be seen as a challenge to other NGOs, and the relationship between SHIP/DMSC and some other NGOs was largely conflictual.

SHIP/DMSC also recognised the importance of getting politicians and other important people on their side and had been successful in garnering public support for their agenda from a wide range of actors in the policy process. A significant factor in the meteoric rise of SHIP and the DMSC within the policy arena was its relationship with the West Bengal Sexual Health Project and by association with DfID. As West Bengal Sexual Health Project's declared 'flagship' project, it benefited from publicity both locally and at national and international levels. An indication of how well known it had become is that, in the mid 1990s, over 300 people a year were visiting the project (personal communication). It also acquired a degree of celebrity, if not notoriety, from the high profile it achieved in national and international policy circles. Certainly the reputed success of the project gave the WBSHP and DfID something tangible with which to publicise their work and its success.

The DMSC was also very effective in organizing and participating in public events. These culminated in 2000 when it held a three day Sex Worker's Millenium Mela in Calcutta to promote their demands for decriminalisation of the sex trade. This achieved a huge amount of media coverage (Banerjee 2007). Further the gap between local and global awareness of the project has been bridged through the publication of a number of articles that have appeared in international peer review journals (Jana & Singha, 1995, Jana et al 1998, Nag 2002, Jana 2004, Madhusree 2006, Basu & Dutta 2008, Evans & Lambert 2008, Ghose et al 2008). Consequently they have achieved a wide audience for their model of intervention.

6.4.4 Alternative approaches and opposing viewpoints

Inevitably the high profile achieved by SHIP and its associated organizations was subject to criticism from other NGOs working with sex workers. There were attempts to stop the Millennium Mela by the Voluntary Health Association of India and Shanlaap, a prominent Kolkata based NGO working on human rights, which held a meeting 'Violence Against Women' to put forward its objections and also petitioned the Governor of West Bengal to have the Mela banned. Although permission was denied 36 hours before event it was reinstated after lobbying from DMSC (Banerjee 2001).

Shanlaap opposed the decriminalisation of sex work arguing that it was overshadowing the human rights issues involved in trafficking. The director of the organization argued that trafficking was politically very sensitive and attempts to get it on the agenda had been resisted by politicians, some of whom were allegedly its beneficiaries. Thus, the focus upon decriminalisation let politicians off the hook and also saved them embarrassment internationally. For Shanlaap which campaigns on behalf of trafficked girl children and women, the key issue was how to persuade State, National and International governments and organizations to face up to the problem of the trafficking of girl children and women, acknowledge the problem and begin to address it (Sleightholme & Sinha 1996). This was a view shared by a number of other NGOs that participated in the study.

It was also felt that the decriminalisation lobby was distorting the argument around local level abuse and maintaining the status quo. Respondents from a number of NGOs working with sex workers, their children and abused and trafficked girls and women maintained that the material living conditions within the brothels of West Bengal remain abysmal and that abuse was continuing. Shanlaap adopted the

position that the commercial sex workers were being manipulated to advocate an agenda that served the interests of the middlemen and women who most benefited from the sex trade. It also argued that there had been no reduction in the numbers of girls trafficked for insertion into the sex trade despite claims by the DMSC that they had effectively eradicated it.

Another criticism coming from within the NGO community was that in reality the organization was controlling all access to the sex workers within the red light districts of West Bengal, and particularly so in Sonagachhi. The DMSC/SHIP were accused of preventing other NGOs from working in the Red Light Districts or from approaching any of their women to participate in research projects. The organization was also said to charge for access to the women and ultimately controlled who spoke to them and what was said. The High profile of SHIP was also felt to be obscuring the work of other NGOs. One NGO specifically asked how it could spread the message of the model that it had developed because lack of visibility was felt to be a big problem, particularly with respect to getting funding.

6.5 Responding to Felt Need

6.5.1 Introduction

At the start of the chapter it was noted that NGOs gained their legitimacy from their ability to respond to the felt needs of vulnerable communities. This study, for the reasons discussed in Chapter Three, did not undertake detailed ethnographic research amongst project users. The respondents from NGOs were asked what *they* believed to be the felt needs of project users and this information was considered with respect to what NGOs said about their interventions and what if anything they wanted to do but were unable to do. This chapter will conclude with a discussion of

the NGO perspectives on responding to felt need and will look at the 'fit' between the discourse of risk and vulnerability in circulation amongst NGOs and their interventions for prevention and control.

6.5.2 NGO interventions

First and foremost there was incongruity between the way the NGOs described the factors giving rise to vulnerability and what they said they were actually doing with respect to prevention and control activities. Without exception, the NGOs saw vulnerability as a consequence of social, economic and cultural practices. The NGOs were split, however, on how they viewed the solution to these problems. The majority of NGOs were providing targeted interventions aimed at STD control, condom programming and Behaviour Change Communication and in this way were applying biomedical and behavioural strategies to deeply embedded structural problems. There was also a significant weakness in the manner in which gender and sexuality were conceptualised within these programmes thus offering a reductive and overly simplistic view of human sexuality.

A small number of the NGOs had explicitly rejected the targeted intervention approach for these reasons and were continuing to work with vulnerable communities on social interventions that addressed their felt needs of project users (as understood by NGO personnel). Thus in several NGOs working with sex workers, considerable focus was placed upon the social welfare and education of their children. Amongst these NGOs there was explicit criticism of the approach for failing to engage with the felt needs of project users and trivializing the problems facing them.

It was interesting to note that at times during interviews the respondents concurred with their project users that while HIV was clearly a threat, there were more immediate concerns. In particular, the day-to-day welfare of their children took precedence over everything else:

We were going from house to house studying and talking to the women about pregnancy, STD, HIV and AIDS. But there were so many other problems in their lives...*then we realised that STD wasn't really a very special thing* so we got a centre for the children more than their mothers and asked them to come... (interview data) [stress added].

For this NGO it was more important to respond to the women's fears for their children than to press on with an STD intervention that wasn't wanted. In the fullness of time they were able to return to the subject of reproductive and sexual health but they explicitly rejected the targeted intervention approach as reductive and unhelpful.

However, a more nuanced picture of how NGOs were engaging with the concept of targeted interventions began to emerge over the course of the study. First, although several NGOs were broadly supportive (or at least uncritical) of the approach, considerable efforts were made to supplement the narrow range of activities with broader based activities. Many of the projects had additional sources of funding and were able to supplement what they were doing. Additional services were wide ranging as one might expect given the reputed ingenuity of NGOs. These included nutritional programmes, the provision of a daily free hot meal, non-formal schools, adult literacy training, income generation and craft projects, health education, legal advice and support and much more. For example, in addition to being provided with meals, schooling and medical care, street children were taken on excursions and days out.

The importance of friendship was stressed repeatedly in projects relating to truck drivers. One project encouraged truckers to use their clinic as a base to socialise and

make friends, ostensibly offering an alternative place to spend time during the tedious days/hours spent waiting for paperwork to be completed. Project workers said that during the previous Durga Puja¹⁹ a group of truckers had rented a storage unit and held a puja celebration to which the programme staff had been invited as a means of returning the hospitality that they, the truckers, had received. On one visit to a truckers' project I saw an elderly woman bring in her young granddaughter, who had a fever and cough, to see the doctor. The doctor, on the point of leaving, stayed behind to examine the girl and dispense some medicines for her.

Another NGO working on a cross border initiative had been very involved in mitigating the damage caused by monsoon flooding in the surrounding villages. They were able to provide flood and disaster services because they have a flexible donor, who it was said, understood that the immediate needs of local communities had to be addressed if other interventions were to be accepted. These examples illustrate that a more holistic approach was being taken to working with vulnerable groups. However, this depended upon the ability of NGOs to secure additional funding. Importantly these sorts of activities did not always feed back into the evaluation process designed by some donors hence they provided an invisible, but arguably essential backdrop to the targeted interventions. Mooni & Sarangi (2005) present a study of an Indian NGO that had taken an ecological approach to working with vulnerable populations. Such an integrated approach to HIV prevention fell outside of the funding criteria of donor agencies. They argue that NGOs need to frame their work in particular ways in order to get funding but acknowledge that NGOs rarely have the power to 'frame up' because this is done by more powerful actors in the policy process.

¹⁹ A major Hindu festival in West Bengal which takes place over three days at the start of winter.

One issue that arose time and again when visiting the projects was that the withdrawal of the budget for drugs for general conditions from WBSHP funded projects had been very detrimental to the relationship between NGOs and project users. This drug budget was felt to be essential, both in practical terms for the project users and also symbolically, because it represented a degree of general concern for the well being of project users that transcended their perceived role in the transmission of HIV. The NGOs were unable to get this back on the agenda and even the PMU team, which advocated for its return, were unsuccessful.

This raises the question of whether NGOs were able to influence the policy agenda. The example given above would suggest that NGOs have less power within the policy environment than such policies imply. This lack of power can be seen in relation to injecting drug users. The use of drugs for recreational purposes is a criminal offence in India and is considered both antisocial and immoral (Panda 2001, Chatterjee et al 2002). NACO policies identify them as a key risk group (NACO 1999, NACO 2000). A number of NGOs were working both on de-addiction and harm reduction within Kolkata/West Bengal. While harm reduction programmes stressed the need for clean needles and the dangers of sharing injecting equipment, needle exchange programmes were generally not part of the targeted approach used with addicts, although one project was offering a needle exchange programme. The PMU said that it could not promote needle exchange programmes amongst NGOs because it was contrary to the government's approach.

Ironically the lack of support services for drug users means that some resorted to giving themselves up to the police as a means of getting off the streets and off drugs for a while, so drug users often find themselves imprisoned on drug related charges. Despite this, at the time of the study, the prison services and State AIDS Society had

not developed any plan of action for the prison population. Some individuals both from within and outside the NGO circuit expressed real concerns over the lack of prevention and control interventions aimed at these individuals but had been unable to get the issue onto the agenda. In West Bengal, at the time of the study, the authorities were largely unsupportive of initiatives geared towards the rehabilitation of drug users and the need for prison security overrode attempts by NGOs to enter prisons and offer support as part of a rehabilitation programme.

In the same way attempts to identify (formerly) drug addicted prisoners in order to offer support upon their release had been unsuccessful. The provision of clean needles and condoms for prisoners has proved hugely controversial, if not untenable, the world over and India is no exception to this. Against a background of deep-rooted social and political approbation, NGOs faced huge challenges in developing prevention and control interventions for drug addicts. Similarly with an overriding concern for law enforcement and the need to uphold prison security rigorously, attempts by NGOs to work with the prison population will only succeed with considerable political support. There was little evidence of this support at the time of the study.

6.5.3 Targeting Men Who Have Sex With Men

Finally the issue of developing targeted interventions for men who have sex with men raised further critical questions about the role of NGOs in HIV programming. At the time of the first phase of field research for this study, there were no NGOs offering interventions of any sort to men who have sex with men although a loose grouping of NGOs and support groups had begun to emerge and a needs assessment was in the pipeline. This was despite the fact that men who have sex with men was a

designated risk group both within the WBSHP and nationally. The reasons for this are complex but cut to the heart of programming strategies.

On a purely technical level the one NGO that expressed an interest from the outset of developing a targeted intervention with WBSHP was too new to receive funds from overseas under FCRA rulings. As a nascent organization, it also lacked the infrastructure and income to fund day-to-day activities while developing core services. While it was able to design a needs assessment and train volunteers to help conduct it, the vast majority of the volunteers melted away once the needs assessment was completed. This was felt to be partly because the volunteers' primary motivation had been the small stipend that they had received for doing the work. Once this dried up, they needed to find other sources of income. The feeling was that the funding agency had failed to understand how critical the issue of funding actually was for the day-to-day survival of the project.

A fundamental issue raised by respondents working in this area was whether there was actually a community as such to work with. It was suggested that in reality, there was no group based identity and that attempts to label and categorise men as either khoti or panthi in order to facilitate a targeted approach was essentially an artefact of the wider public health discourse (Boyce et al 2007). Closely related to this was the fact that an essential survival strategy for men who have sex with men was their ability to 'pass' when in public. Thus the attention that the needs assessment and such like brought with it was unwelcome. This was something that one respondent said was poorly understood by the donor funding the needs assessment. There had been repeated requests to accompany project workers to cruising sites so that representatives of the donor could see at first hand what the

men did there. This voyeurism masquerading as scientific interest was resented by project staff and undermined the development of trust with the donor.

All of the above factors undoubtedly did affect the ability of these NGOs to develop any targeted interventions. However, at least one donor argued that he had 'bent over backwards' to try and facilitate the development of an intervention but that the capacity for such work simply did not exist within the state. Furthermore this donor had been bound by the terms of their own funding source to fund only certain things, although it had interpreted the guidelines as loosely as possible.

A further complication was the vulnerable legal status of the men being targeted and the harassment that they were subject to from police and local hoodlums. The director of the State AIDS Society was asked about ways in which it might try and protect these men from the wide scale abuse that they suffered. His response was that no politician would ever promote a change in the law and that first NGOs had to change public opinion on the subject (see section 5.4.3 regarding the recent repeal of this law). Thus NGOs were in a 'catch twenty-two situation' with the state refusing to act until NGOs had changed public opinion but NGOs understandably unwilling to act until they had the protection of the law and broad based public support.

Inevitably therefore, there was an implied reluctance from within these NGOs to develop capacity in the delivery of targeted interventions. One respondent discussed at some length the need to offer a safe space where men could come and talk without any set agenda on the part of the organization. The need for community-based interventions was something that might occur naturally later on but only after the groundwork had been done. This required time and critically secure funding that could be used for general purposes without having to implement programmes for public health.

6.6 Concluding comments

This chapter began by reviewing the characteristics of NGOs that reputedly make them ideally suited to work with vulnerable groups on HIV/AIDS programming. These included the ability to identify hard to reach and marginalized groups and develop working relationships with them, to respond to the felt needs of group members and the capacity to fight for and promote the human rights of these groups (Mercer et al 1991, Asthana & Oostvogels 1996, United Nations 1996). Certainly, the groups identified by the NGOs in the study were highly stigmatised and lived on the peripheries of society. Respondents repeatedly drew links between the poverty, stigma and inequality experienced by group members and their vulnerability to infection from HIV.

On closer analysis, there seemed to be a significant occupational basis to risk groups and in many cases migration or mobility was also implicated. One could speculate on whether this had a basis in caste not fully recognised by the researcher or an Un-Bengali slant again not fully identified by the researcher at the time of the study. Certainly a recurrent factor in being marked out as being at risk was the relative power or lack of it experienced by group members in relation to the NGOs in the study.

While it is not suggested that the groups identified were not at risk from infection, the inability or unwillingness of NGOs to look for risk and vulnerability amongst more powerful members of society was very marked. Similarly, by focusing narrowly on a small number of groups, the potential to reach the whole of society has been lost. This had entrenched hard line and discriminatory attitudes to those infected/affected by HIV and contributed to an 'othering' of the epidemic. It had also

distorted the picture of infection at a time when some doctors were seeing evidence for an already disseminated epidemic warranting a completely different approach to prevention and education.

Power relationships cut to the heart of these risk groups and inevitably they also impacted upon the manner in which targeted interventions have been implemented. The need to promote human rights, an essential characteristic of NGOs has been significantly undermined by an unwillingness or inability to challenge the status quo or question the social, political and economic structures that give rise to vulnerability in the first place.

Furthermore, the exploration of the competing approaches to working with sex workers, found in the models of DMSC and Shanlaap, clearly illustrates that it can be impossible to reach consensus about what a human rights based approach to prevention and control might actually entail. Thus for members of the DMSC the decriminalisation of sex work and the recognition of it as a profession was presented as a claim for their essential human rights to be recognised, specifically the right for autonomy and control over their bodies and their lives. For Shanlaap these demands were understood to be further evidence of the erosion of the human rights of sex workers - a claim for sexual servitude driven by the agenda of powerful factions within the sex trade who stood to gain financially if these demands came to fruition.

Despite a good awareness of the structural factors affecting vulnerability within risk groups the NGOs in the study were working largely within a biomedical model with respect to targeted interventions. Notwithstanding this, in many cases NGOs were making significant attempts to support project users in a significantly more holistic, nuanced and humanistic way. Unfortunately much of this work relied upon securing alternate forms of funding and despite its perceived importance amongst

respondents, there was a shared sense that the message was failing to get to the wider policy community. NGOs lacked the power to 'frame' their interventions and give weight to the multiple strategies and services that they provided (Mooney & Sarangi 2005). This problem is recognised by Porter et al (2004) who note that whilst NGOs often play an important role in disease control programmes they are prevented from sharing their experience and knowledge because of the mechanisms in place for the transfer of knowledge. Thus they are unable to influence the policy process. Finally it was clear that in many instances, despite the continued efforts of a small number of committed NGOs, there was a lack of state level commitment to support and develop interventions with some of the most stigmatised groups such as drug users and men who have sex with men. The following chapter will explore the implications of these factors for the provision of care and support for those infected with HIV.

Chapter 7

NGOs and the provision of Care and Support for People Living With HIV/AIDS.

7.1 Introduction

The preceding chapter explored how NGOs in West Bengal identified risk groups with which to work on targeted interventions during NACP1 and NACP2. NGOs in the study were explicit in their identification of a range of social, cultural and notably, economic factors that contributed to vulnerability amongst project users. Poverty, pre-existing stigmatizing identities and the discriminatory practices arising from these were heavily implicated in the classification of risk groups. These are structural factors. Yet, prevention and control activities tended to focus upon a limited range of biomedical and behavioural interventions aimed at bringing about individual behaviour change. On closer examination, however, it was evident that many NGOs were trying to address the problem holistically by providing a range of supportive services to project users. These services were not necessarily conceptualized as part of their HIV programme but were understood, within the context of the project, to be essential if HIV interventions themselves were to be accepted by targeted groups. They were also seen to have value for project users in and of themselves. The difficulty faced by these NGOs was that they were circumscribed by the funding priorities of donors. They also faced the challenge of getting their experience and expertise recognised by other actors in the policy process and, in doing so, contributing to overall understandings of HIV/AIDS and the development of policy responses.

In West Bengal, as elsewhere in India, study participants reported stigmatization and discrimination against both members of risk groups and those infected with HIV (Bharat 1999, Human Rights Watch 2002, D'Cruz 2003). This has happened throughout the world (Barnett & Whiteside 2002; Parker & Aggleton 2003). By the mid-1990s international guidelines were stressing the need to embrace a human rights based approach to the epidemic if prevention and control activities were to be successful. This included providing care and support for people living with HIV/AIDS (United Nations General Assembly 2001). Lampley (2002) sums up the importance of care and support thus:

An effective HIV prevention programme is one that is comprehensive and that addresses a community's prevention, care and treatment needs. Essential components of a comprehensive programme include HIV testing and voluntary counselling, prevention of mother to child transmission, clinical care and antiretroviral treatment... (Lampley 2002: 210).

This makes it clear that, whilst formerly neglected, care and support was an area that needed to be addressed both from a human rights perspective but also because of the positive impact upon reducing stigma and helping to prevent further spread of the infection. The provision of care and support for those infected/affected with HIV/AIDS was identified as a priority in NACP2. However it was unclear how care and support services were to be developed. At the time of the study the pandemic in India had been constructed as predominantly affecting the poor and socially marginalized members of society. These people already had problems accessing health services and it was expected that the majority of affected people would be too poor to bear the financial burden of the disease (World Bank 1999b). Pre-existing barriers to equity and access were compounded by the discriminatory behaviour of health care providers in both the private and the public sectors (Bharat 1999, D'Cruz 2003, Paul, 2007). This had implications for the manner in which care and support

services were conceptualized and designed. Hence a role was developed for NGOs in the provision of care and support services (NACO 1999, NACO 2000). Both NACO and the World Bank stressed the need to target members of risk groups with care and support services, and to develop them along lines that will make them accessible to the most vulnerable and excluded. Emphasis was thus placed upon NGOs to do much of the caring under the rubric of Low Cost Models for Home and Community-Based Care and Support (Interview World Bank). The World Bank's position was that it had a particular interest in assessing these models and promoting those that were successful (interview data World Bank).

Against this background, this chapter is concerned with the ways in which local level NGOs in West Bengal engaged with the need to provide care and support for those infected/affected by HIV/AIDS. Section 7.2 will consider the manner in which the epidemic was constructed as one where 'the only cure is prevention' (WBSHP 199, Piot 2001). The sentiment contained within this popular slogan used in awareness campaigns and educational material significantly influenced the willingness/capacity of NGOs to address potential care and support needs of projects users. At the heart of this lay a number of intersecting and overlapping discourses reflecting different understandings of HIV/AIDS and of NGOs themselves.

Section 7.3 looks at the ways in which NGOs in West Bengal at the time of the study identified the provision of care and support as an area that they needed to address and why. This includes looking at attitudes towards HIV testing and the ability of NGOs to identify people who might be in need of care and support. This section will also look in detail at the work of a small group of NGOs that was providing care and support. At the time of the study, the terms of the debate around care and support were clearly demarcated to rule out NGOs developing care services

that incorporated the treatment of Opportunistic Infections (OIs) or the provision of ART (NACO 2000). This is not necessarily a bad thing if these services are provided elsewhere (for example at the time of the study Calcutta Medical College was receiving some ring-fenced funding for the treatment of OIs from the SAS). However, it does throw up other complications. For example how are issues of equity and access to be resolved and how will members of socially marginalized groups access care and support if they need to? Leading on from this section 7.4 will consider the relationship between NGOs and other actors involved in the design and delivery of health care at the state level and identify a number of factors that have enabled or constrained their work in this area.

7.1.2 Inter-subjectivity and the nurse/researcher divide

First, however, I want to refocus on an issue raised in chapter 3 regarding my own positioning within the research as both a researcher and a nurse. As I stated in chapter 3 there were many ways in which this dual identity influenced the course of my research and my understandings of it. This was particularly true with respect to the subject of care and support. A primary concern for me at the time of the field research was my inability to reconcile my own experiences of nursing people with AIDS related illnesses in the UK and descriptions and accounts given by respondents concerning their experiences of this. At the time of the study there was still very little published on patterns and incidence of HIV related disease in India although the link between TB and AIDS had been made. I was frequently mindful of how terribly ill the people that I had nursed in the UK were, prior to the introduction of ART. It had been incredibly difficult to provide good holistic care irrespective of being at that point very experienced, highly skilled, highly motivated and working in a supportive clinical environment. This remains a complex issue for me. I remember

feeling frustrated by what seemed, to me, to be esoteric and fairly meaningless debates about the nature of community and home-based care at the level of the state and also within national and international policies. Meanwhile many of the respondents within NGOs seemed to lack the skills and experience to be able to contribute to the debate. In the previous draft of this thesis I cited a number of examples regarding my interaction with study participants concerning this issue. What strikes me now in reading these sections is how much these passages reveal my own difficult feelings about the research and my anger, very broadly stated, about the nature of the world that we live in and the injustices that people suffer.

Whilst I do not think it necessary to elaborate on this further, I believe it is true that these feelings influenced the manner in which I interpreted some of the data in the first submitted version of this study. I focused very heavily upon the role of the World Bank in this respect, as was made clear to me during the course of my viva. As such I have, in the intervening months returned to my primary sources, research diaries and secondary literature in an effort to untangle some of these interrelated issues²⁰. As such this chapter now begins by looking at a number of different discourses implicated in the understandings of what care and support might entail in the context of West Bengal. In addition to looking at the role of the World Bank I have also considered Indian responses and understandings to HIV/AIDS and the context within which these have emerged. In chapter 8, when I review the study methodology, I return to the researcher/professional.

²⁰ Ballinger (2003) and Finlay and Gough (2007) note that knowledge emerges constantly throughout the research process.

7.2 The framing of care and support

7.2.1 Background to care and support in India

The early policy response to HIV/AIDS in India focused on the need for prevention and control activities and little attention was paid at the government level (both central and states) to the need for providing care (Gupta & Panda 2002). When care and support was addressed it was largely reduced to the provision of counselling. By the time that the fieldwork for this study was undertaken, care and support for those affected/infected with HIV/AIDS was beginning to garner attention at the international/national levels and there was a growing awareness that the success of prevention and control activities depends upon access to appropriate care and support services (United Nations General Assembly 2001).

India's NACP2 responded to this by highlighting the need to develop Low Cost Models for Community and Home Based Care and Support with the stated intention of publicising and replicating successful models. While noting that NGOs were being under-utilized in this area, it was anticipated that they would play an increasing part in the provision of care and support, particularly with regards to poor and marginalized members of risk groups relying upon community and home based care (NACO 2000). However, these plans were vague, and individual states were expected to develop their own policies according to local need. NACP2 did allocate some ring-fenced funding for drugs to treat opportunistic infections. This was to be made available via the state sector (NACO 2000). Attempts to 'normalize' the epidemic included the move away from designated AIDS wards to caring for individuals wherever most clinically appropriate.

NACP2 explicitly rejected any movement towards the provision of Anti Retroviral Therapy (NACO 2000). The World Bank in its appraisal document for NACP2 argued strongly against giving in to the pressure of a powerful minority demanding ART, stating that the provision of ART would drain the drug budget and fail to offer any real benefits:

Providing Western-based treatment and care of AIDS cases for example triple anti-retroviral therapy was rejected [as an option]...these treatments are hugely expensive, remain palliative and are unlikely to have an impact upon HIV transmission. (World Bank 1999b: 11).

It is important to point out that the situation concerning the provision of ART has significantly changed since the time period for this study²¹. However, to reiterate, during the time frame of the study it was firmly off the agenda.

Unsurprisingly then, at the time of the study care and support continued to be an area afforded a low priority in West Bengal. Clearly the emphasis on prevention and control at the national level played a part in this, but an overriding assumption seemed to be that prevention and control strategies were successful, that infection rates remained low and that consequently very few people were presenting with HIV/AIDS related illnesses (see section 5.3). The prevailing climate was one in which there was a lack of urgency about developing care and support services. Essentially, it was argued that when the need arose for care and support services to be developed action would be taken but until then it was unnecessary. This may have been in part due to an Un-Bengali discourse in circulation.

²¹ The cost of ART had come down considerably by 2000 (Shadlen 2007). The WHO has spearheaded a public health approach to the provision of ART (Kitahata et al 2002) to overcome some of the barriers to access such as problems with delivery systems and drug resistance. In September 2003 the WHO declared the lack of ART a global health emergency and along with UNAIDS launched the 3 by 5 initiative (the provision of ART to 3 million people in the developing world by 2005) (Muthuswamy 2005). This was followed in 2005 by the G8 summit in Gleneagles setting a target for universal access to ART by 2010. NACO responded to these changes in 2004 by rolling out a programme to provide ART in government hospitals in the six high prevalence states (Sheikh et al 2006).

Some doctors, however, were reporting an increasing number of patients presenting with AIDS related illnesses and therefore they refuted this view. Many of these infected individuals fell outside of targeted groups suggesting a generalized epidemic had already developed in West Bengal (Interview data). However this position was not supported by data collected for the purposes of sentinel surveillance and the number of reported AIDS cases remained low. It is impossible to state the extent to which HIV/AIDS related morbidity and mortality was going undetected or unreported in West Bengal at this time. While it was accepted at the national level that reported cases were the tip of the iceberg, the response of West Bengal's State AIDS Society continued to be that HIV/AIDS related illness was not as yet a problem (interview data).

7.2.2 Care and Support - a lack of options

As has been discussed already, HIV/AIDS was constructed as a disease of poverty and deviancy, one for which there was no treatment and no cure. For example one government campaign adopted the slogan 'AIDS equals Death' to convey the message that there was no hope for somebody once they became infected (Dube 2000, Bharat & Aggleton 2002). Public health messages stressing that 'prevention is the only cure' (WBSHP 1999: 45) and scare stories in the media contributed to a situation where HIV/AIDS was the cause of considerable fear and those infected, or believed to be, so were highly stigmatised and discriminated against (Priya 1994a, Bharat 1999, Paul 2007). Priyya (1994a) has called this 'the panic reaction'. A good example of this approach to the pandemic can be seen in an information booklet published by the West Bengal Department of Health and Family Welfare on behalf of West Bengal SAS in June 1999. Entitled *AIDS: A Dreadful But Preventable Disease*, the preface contains the following statement '...the stark reality is that a

person afflicted with this disease has nothing to look up to but impending death'. It then goes on to note that:

We should remember that the AIDS patients too are members of our society and family. They can naturally expect humane behaviour from us. Humane behaviour with the AIDS patients is, therefore, as much our social obligation as prevention of AIDS (West Bengal State AIDS Prevention and Control Society 1999: preface).

These two excerpts encapsulate the tension and contradictions that lay at the heart of the prevention and control strategy adopted both nationally and locally during NACPI and NACP2. Essentially fear was used as a strategy to promote behaviour change, adopting the 'prevention is the only cure message' as a means to this end. This was despite evidence that scare tactics do not work and are likely to make the problem worse (Danziger 1994).

Whilst the provision of care and support for infected individuals would have gone some way towards mitigating some of the panic and fear associated with HIV infection, the reality for the majority of people was that there was nothing available for them if they became infected. Local communities with the support of NGOs were expected to respond to the needs of infected community members. Hence the exhortations in the quotation above to treat those infected humanely. Thus the preface engages with and reinforces the type of message that has contributed to the 'othering' of the epidemic while simultaneously asking that people ignore this message when faced with individuals suffering from AIDS. It was within this inherently contradictory discursive space that NGOs were expected to develop the conceptual and practical skills to offer care and support services.

7.2.3 A Discourse of Despair

Arguably, a sense of hopelessness and despair informed this policy position and much of the material in circulation both for training purposes and for Behaviour

Change Communication reflected this. For example a training manual on HIV/AIDS produced by the WBSHP contains the following statement:

So far there is no cure for AIDS and a vaccine for prevention of the infection may be far away. Even if there were a cure, the cost of medicines might prevent it from being used in many developing countries. For example combination therapy, one method for treating HIV, is estimated to cost US \$44,000 per year. (WBSHP 1999d: 44).

The availability of effective treatments for many opportunistic infections seemed to have been over looked generally at this time. Certainly it seemed from interviews conducted within NGOs, that respondents assumed that ART was the only treatment option and therefore the treatment of opportunistic infections was not really on the agenda either. Of course, there is always the potential or possibility for pre-eminent modes of thinking to be challenged and discourses are not static entities (Carabine 2001). One NGO working actively in the field of care and support was clearly engaging with and simultaneously challenging this discourse of despair when it chose to entitle a booklet detailing its activities in the field of HIV/AIDS as *Looking Ahead Positively* (Bhoruka, undated). This NGO had been able to develop services to the extent that they had something tangible to offer project users. The following section will explore some of the discourses implicated in constructing HIV/AIDS in the Indian context as a disease without hope.

7.2.4.1 The World Bank Approach

The approach to care and support described above was adopted by both the World Bank and NACO at the time (World Bank 1999a, NACO 2000). As such it represented the complex interplay between, on the one hand, biomedicine and what was technically and scientifically possible and, on the other hand, economic imperatives and what was acceptable or positively desirable within policy circles. Biomedical understandings of HIV/AIDS were privileged as a framing device. For

example, the stress that nothing can be done in the absence of a vaccine presents the problem as one that cannot be solved with biomedical technologies. However, a number of other perspectives and understandings of the issue were also implicated.

The World Bank's approach to HIV/AIDS offered an economic rationale for policy options. As such prevention and treatment were conceptualized as two competing demands for limited resources. Using the Disability Adjusted Life Year²² as a means of identifying preferred policy options, prevention programmes were considered to be more cost-effective than treatment based programmes (World Bank 1999b, Das 2009). Thus the project appraisal document produced by the World Bank to introduce their approach to, and rationale for, NACP2 contains an appendix with the DALY scores allocated to different types of interventions (World Bank 1999b).

7.2.4.2 Indian responses

As was noted earlier, when discussing the impact of globalization and liberalization on India, the role of the World Bank in influencing health policy and setting priorities for public health spending have been widely criticised both within and outside of India. For example Baru and Jessani make the following observation:

In the Indian context, it is apparent that the Bank's policy has distorted priorities as far as communicable disease programmes are concerned. Excessive importance had been given to AIDS and a vertical approach is once again being advocated, which in the past has failed. During the early nineties, the Bank allocated more for Aids and tuberculosis than malaria or other diseases (Baru & Jessani 2000:183).

Priya (1994a) also makes the observation that the morbidity and mortality associated with HIV/AIDS needs to be placed within the context of other causes of ill health. As such he argues that HIV/AIDS needs to be understood as one disease

²² Priya (2001) offers the following definition of the Disability Adjusted Life Year (DALY) 'DALY's is a composite index quantitatively representing "burden of disease" incorporating in one figure morbidity, disability and motality, expressed in terms of estimated years of human life affected' (Priya 2001:155).

amongst many others in India. Against this background it is worth re-stating that for the poorer sections of Indian society health care is extremely difficult to access, and the prevalence of high rates of infectious and non-communicable diseases, is emblematic of a general failure in health service delivery. Studies suggest that the primary mechanism for caring for a sick or dependent adult is at the household level. As Pryyia & Sathyamala (2007) highlight, care and support for adults from poor households with long-term illnesses comes primarily from families with addition community support and the support of social networks. Therefore the focus on Home and Community Based Care and Support for People living with HIV/AIDS is entirely consistent with strategies already developed for coping with illness. This suggests the need for a re-framing of the problem of care and support, to one of equity and access to health services for poorer people in India. This, ironically, is an issue that the World Bank has identified as a priority in India (Peters et al 2000).

Certainly it helps to understand why the lack of provision of care for those infected with HIV/AIDS might not have been high on the political agenda. There was no equivalent of South Africa's Treatment Action Campaign in India for the provision of ART. During my field research it was evident that it was generally accepted that people would not receive care. This was in large measure premised upon the understanding that the existing health care system was unable to provide for the health needs of individuals even before the emergence of HIV/AIDS. Thus the focus of much criticism of the World Bank, from within India, was related to the emphasis placed on HIV/AIDS prevention (Baru & Jessani 2000, Banerjee 1999). It was not challenged on the grounds that the money should be spent on care and support for people infected with HIV. Ironically the World Bank's approach to care and support

intersected with an Indian perspective on disease control priorities and the provision of health care.

In addition to this understanding of HIV/AIDS as but one, of many, health problems in the context of inadequate health sector provision, the focus placed upon HIV/AIDS within NACO policies has also been criticised. Chapter four looked in some detail at the manner in which a neo-colonial discourse had been identified by a number of commentators in India. As such it has been argued that with the advent of globalization and economic liberalization, India was being used as a market for the products of multi-national companies (for example disposable syringes, HIV testing kits and blood components separators). Linked to this was a deep suspicion that the advent of ART would further this economic exploitation. Thus one journal article suggested that 'Global AIDS conferences have now degenerated into promotion campaigns for therapies' (Prasannan 1998: 5). Therefore the resistance to the introduction to ART can be seen to have originated both from the international level and from within India. Furthermore NGOs were explicitly linked to this neo-colonial reading of the pandemic and were implicated by their association with foreign donors. Whilst it is true that the World Bank's approach to HIV/AIDS closed down a number of treatment options, this perspective that ART was too expensive and inappropriate within the context of India, also informed Indian responses to HIV.

7.3 Identifying need in project users

Against this background studies from elsewhere in the world suggest that where HIV is highly stigmatised, individuals who are infected, or believe themselves to be, tend to go 'underground' concealing their HIV status or choosing not to undergo a test or access health care. This can militate against prevention and control (UNAIDS 2000). This is particularly the case when there is little on offer in terms of care and support. In order to ascertain how much contact the NGOs in the study actually had with HIV infected individuals, respondents were asked whether they personally knew of any project users who were HIV positive or had become ill or died from an AIDS related illness. The majority stated that they knew of nobody who fitted these criteria. Several respondents did however have their suspicions that a project user was HIV positive. Typical comments were:

She went back to her village and then we heard that she had died. We suspected but we didn't know ...

All of a sudden they disappear. One girl who was very close to us she was gone for a few months. Then she said 'Oh I had gone to someone's apartment'. And then we heard that she had died. When the girls know that they have HIV they give up.

Some respondents working with injecting drug users suspected that a project user or users may have developed an AIDS related illness but they couldn't say for sure because these individuals had left the location either to return for a short period of time or not at all. One respondent involved in a needle exchange programme said that he had watched injecting drug users become sicker and sicker but he could only guess why.

That so few of the NGOs were aware of people living with HIV/AIDS in their midst is a particularly alarming state of affairs, not only because the success of HIV/AIDS

prevention and control activities has been closely linked to the provision of care and support services (UNGASS 2001), but also because of the human suffering implied (Kallings 2008). Although three of the NGOs had established support groups for people living with HIV/AIDS none of the other NGOs had any plans to do so. Evidently the ability of NGOs to take an active role in the provision of care and support is premised upon the assumption that they will know of those individuals who actually need care and support. This situation also belies the claim that NGOs can act on behalf of, or represent, the needs of these individuals. In reality the majority of NGOs in the study lacked any representation from people living with HIV/AIDS.

This latter point has a number of consequences. In order to provide appropriate support services that respond to felt need, it is essential that people living with HIV/AIDS are able to say what it is that they need and want, as opposed to policy makers assuming that they already know. Further, this situation prevents people within the NGO from developing their knowledge and skills in helping people infected/affected to deal with the problems that they face. Finally it has been suggested that NGOs could advocate for the people that they serve (World Bank 1999a). Instead the situation described above reinforced the perception at the state level that the provision of care and support was relatively unimportant because NGOs were not seeing a need for it amongst their project users.

Essentially these NGOs were functioning in a climate where, rather than linking prevention and control with care and support, the success of the former was seen to exclude any need for the later. This may in part, reflect anxieties over funding and the perceived need to remain positive about the benefits of targeted interventions. The fact that targeted individuals might already be infected with HIV or that they

might subsequently get infected, didn't seem to be recognized. This was despite the fact that some of the NGOs had carried out needs assessments in the planning phase of the project, where anonymous unlinked HIV testing had been carried out in target populations, and infection had been found. Likewise, as chapter 5 indicated, the NGOs had a detailed understanding of the vulnerability and risk factors of their targeted populations.

7.4 What does care and support entail?

HIV/AIDS has been described as a spectral disease (Gilks 2001). However this may not be obvious within the context of resource poor settings, if weaknesses in surveillance and diagnosis lead to it being invisible except at the very end of an individual's life. It is important that the difference between infection with HIV and AIDS is recognised and that care is tailored to the different stages of the infection. The term 'continuum of care' has been adopted to describe this dynamic process. Care across the continuum should cover a broad spectrum of activities, not simply home-based care. This point is highlighted by Gilks:

Focusing on AIDS alone reinforces the negative, that we have little control over this disease, and can do very little good, rather than the positive, that much early disease is successfully treated and that even with basic drugs and facilities something can always be done.... (Gilks 2001: 178).

Thus care should include pre and post-test counselling and psychological support for those affected/infected, social support (for example, helping to overcome discrimination in the home, workplace and wider community) and care for those experiencing the physical manifestations of infection. How these are linked and what services are available will depend upon the orientation of the NGO, its skills base, access to funding and its relationship with other actors involved in the

provision of health and social services as well as the acceptance of the community within which the NGO is working.

It is both unreasonable and impractical to expect all NGOs to provide all services. In an ideal situation an NGO will be able to provide input into some or all of these *or* have developed sufficiently good working relationships with other NGOs or service providers so that individuals can be referred on if necessary. In the latter scenario, the NGO fulfils an additional role as coordinator or facilitator of care. This can be complex and demands good networking and inter-organizational communication skills and a large degree of credibility with, and acceptance by, the organizations they will be referring to. It is worth reiterating at this point that most of the NGOs involved in the study did not have a background in health care.

7.5 Care and support: NGO approaches

Despite the problems identified above, three NGOs were working on providing care and support and a further two either hoped or expected to be doing so in the future. Of these NGOs, the latter two were already involved in providing a broad range of health care services for socially marginalized and poor populations. One was at the stage of drawing up a policy to deal with issues relating to HIV testing and the provision of treatment for opportunistic infections. The principal issue was of how to deal with the financial implications of extending their remit into this area, and ways were being sought of developing links with other NGOs and the state health care system. It was accepted unquestioningly that ART would not be an option for their patient as discussed earlier. The second NGO already had an inpatient care facility with links to the state at the district level and was hoping to get funding for provision of designated beds for people with HIV related infections. At the time of

the study, this was still at the planning stage and so no further information is available.

Of the three NGOs actively working in this field, each had a different reason for recognising the need for care and support. The NGO with the most evolved programme had, as a significant part of its activities, a charitable blood bank. The former director, a haematologist, had experience of working on HIV in a different setting and, when HIV testing kits became available in India she initiated the testing of all donated blood. When HIV infection was found in donors the organization began to develop support services for them.

The second NGO was working with abused and trafficked girls and women. HIV/AIDS related activities were only one part of their remit. Part of their work involved running shelter homes for rescued girls who had been involved in the commercial sex industry. Some of these girls had been referred on from government remand homes after having been tested and found to be positive. The NGO had also become aware of other women who were not commercial sex workers but were HIV positive and had approached them for help. These women were in the most part married but too poor to be able to afford any health care.

The third NGO provided free and confidential HIV testing services and a support group for people living with HIV/AIDS and their friends. This NGO had developed because a group of people who already had some contact with HIV/AIDS related services in Calcutta were concerned that there was a lack of good quality counselling and support for people who knew themselves to be HIV positive and that these people were very isolated. It was the only NGO that seemed to have developed with the participation of people actually infected or affected by HIV and it also included physicians with experience of working with people with HIV/AIDS and the public

health aspects of HIV/AIDS. Individuals could self refer and the NGO advertised its services in the Calcutta press.

7.5.1 HIV testing and pre-and-post test counselling

The majority of individuals living with HIV infection in developing countries are unaware of their diagnosis (Banerjee 2005). This is problematic because knowing your HIV status is the starting point for accessing a continuum of care (Gilkes 2001). Despite this the majority of respondents from NGOs viewed HIV testing in a negative light and there was a tendency either to avoid the issue or to discourage project users from undergoing testing. As one respondent succinctly put it ‘...we don’t want to get into HIV testing. We don’t believe in that. We believe in human rights...’.

This position was in part a response to a number of problems associated with pre and post-test counselling. In particular it was noted that counselling was often entirely absent. There had also been an increase in private laboratories offering testing services and this took the form of a blood test without any counselling. When counselling did take place, the emphasis often focused upon the perceived wrong doing of the individual and the fact that they were going to die and had brought this misfortune upon themselves. One respondent said:

...This is the manner that they will be told 'You know you have [sic] HIV positive?' and you know most of the people who counsel them don't even know about counselling and they will just say 'how did you get this bad disease? Where did you get it? See what you have done! You are going to die. Do you know that?' And it is a shock for these girls...

Few of the NGOs were themselves involved in counselling associated with HIV testing and for the most part counselling took place after people already knew his or her status. At this stage they may be in considerable distress and have been given inaccurate or incorrect information.

The second problem associated with HIV testing was that the NGOs felt that they were not in a position to offer care to those found to be positive. As a result, there were no perceivable benefits for somebody in knowing his or her HIV status. This is obviously a reflection both of the knowledge they had of the virus and the pervasive policy climate. One respondent working with commercial sex workers said:

...We don't believe in blood testing because we don't think that blood testing has any use... This is what we think. Even if you have it or don't have it use a condom. Even if they have it they are not in a position to stop this work are they?

Closely allied to this was the belief that people found to be HIV positive were treated very badly and in the absence of care had nothing to gain from knowing their HIV status and that it simply represented an additional burden to be borne. As one respondent stated:

In the city as a whole people who test positive are treated like shit. People are vulnerable during this period [when undergoing HIV testing] and suicides have resulted.

One response to this situation was that some of the NGOs accompanied a person undergoing HIV testing and then collected the results for them so that they got the results from the NGO rather than from the testing centre.

7.5.2 Other forms of psychological support

All three of the NGOs discussed above offered a range of counselling and support services. It was noted that most of the people they encountered had learned of their HIV status from another source and were in a state of acute distress when they first came in contact the NGO. This was generally related to what they had been told when given their test results, or what they had heard about HIV from other sources. In particular they expressed fear at their impending death. HIV seemed to be used interchangeably with AIDS and this led many people to believe that they faced immanent death.

Another major cause of distress was the response they had received from their family. This was particularly true of women. Most of the women had either learned of their status when pregnant, (either because they had become unwell during the course of the pregnancy or because they had been given a test without their knowledge), or because their husband had developed an AIDS-related illness and they had subsequently been tested themselves. For these women a significant problem related to how their in-laws treated them, and the abuse and discrimination that they experienced within the home. Counselling was seen as a way of fostering a more positive and supportive attitude amongst relatives. This was often linked to providing information about the manner in which the infection was spread to dispel fears that sharing household instruments, eating together or using the same latrine could spread the infection.

One of the NGOs also offered telephone-counselling. Many of the calls received came from men who had had a recent sexual encounter and were subsequently panicking that they might have contracted HIV. Other callers had heard about AIDS and began to worry once they became unwell. The respondent who took these calls

said that the men often had little or no idea about safer sex and were encouraged to come to the centre to discuss the issue face to face. HIV testing was offered to these men once their particular risks and vulnerabilities had been assessed. The respondent said that these men were generally very uninformed about sexuality and sexual health and had often tried home treatments for the symptoms of STDS such as bathing their genitals in disinfectant or coca cola before seeking help. They also encouraged these men to discuss the issue with their wives and other sexual partners although there was a marked reluctance on the part of the men to do this.

Two of the NGOs had developed support groups for HIV positive individuals where they were encouraged to talk about their feelings and fears and share their experiences:

...and in a group also we give counselling . It's not counselling in the real sense of the word...we just talk [sic] their problems, because many of their problems are common like receiving hatred from their family or receiving a bad attitude from their near ones. These problems are common to most of the positive patients and sometimes the family also goes through some type of crisis.

This was felt to help people overcome their feelings of isolation and gain some feeling of self worth through the support that they were able to give to others.

A third NGO had developed for HIV positive individuals and their friends. This had allowed people to come together in a mutually supportive environment without necessarily disclosing their HIV status. This did not mean that all people attending the support group concealed their HIV status, but the inclusion of friends allowed people to make a decision about if and when they were going to share the information with the group. There was some representation of HIV positive individuals within the NGO itself.

7.5.3 Accessing formal health care services

A frequent concern of NGO representatives from the projects providing support for HIV positive individuals was that hospitals refused to admit those who were HIV positive or suffering from an AIDS related illness. Private hospitals and nursing homes were notably worse in this respect. One respondent told of how she had been unable to get a young woman admitted to hospital who needed intravenous fluids and oxygen. The woman died before a hospital bed could be found for her. Another discussed the difficulty of providing nursing care for people with AIDS who were living at home when their care requirements exceeded the capabilities of their family and where professional nursing was required. This respondent noted that, at the start of their project, they had been unable to get patients admitted to hospital or to get nurses to go to the homes because none of the private nursing bureau that the NGO contacted had any nurses who were willing to provide care for AIDS patients. Another said:

You know our girls, one girl died. It was an emergency situation. We really have to pull strings to get them into hospital.

An additional problem was experienced once a HIV positive person was admitted to hospital or a nursing home ‘...whenever the nursing home gets to know that he or she is an HIV positive patient they throw them out from the nursing home’. This led relatives to lie about the HIV status of the patient. This often resulted in the patients HIV status being discovered after admission and the patient being discharged before their condition had improved. Respondents were unclear about how the HIV status of patients became known within the hospital or nursing home but it was suspected that patients were being tested without their knowledge.

In general the NGOs expressed concern about the standard of care given in the government hospitals. The fact that certain wards were known to be AIDS wards and that simply by being admitted to one an individual or their family could become identified and stigmatised was also raised. There were also issues raised about confidentiality. For example one respondent spoke of visiting a patient who had his HIV status written on a plaster and stuck to his forehead.

7.5.4 Community and home-based care and support

Given the situation outlined above, it is not surprising that two of the NGOs that had HIV positive project users identified the need for access to inpatient services and appropriately skilled staff at the time of acute illness as a priority. One of the NGOs had developed several strategies for achieving this goal. These included the training of twenty-eight nurses employed by a nursing bureau in the clinical management of patients with HIV/AIDS related illness. At the end of this course the nurses expressed a willingness to provide care in a home-based situation. They also ran two-day courses for other NGOs on providing community and home based care in resource poor settings. The organization had also been able to identify one nursing home that was willing to take HIV positive individuals and had provided training for staff.

In addition to this, this NGO had established a two-bedded in-patient facility. This had been difficult to find funding for but by the latter stage of the study was up and running. Whereas in other parts of the country there have been reported difficulties in finding suitable premises due to hostility from the local community, the NGO said that they had had no difficulties in that respect. A second NGO also expressed the desire to establish a hospice and had found suitable premises. However it had been unable to secure funding. This NGO had however, developed a home-based

extension team. The home-based extension team consists primarily of social workers that had received training in hygiene, infection control measures, nutrition and counselling. Despite the fact that some nurses had received training from the NGO none were employed by it. There seemed to be a general lack of nurses but the reasons for this were unclear. There were doctors who were available to make home visits to some patients, but the provision of nursing support for patients and their families in a home-based situation did not seem to be a feature of the programme.

One respondent noted that:

Social workers and outreach workers go to the patient's home and help them with nutrition and health misconceptions ... also if they need medical advice our social workers they know a bit about opportunistic infections...we do not have adequate staff among them so we cannot do it on a large scale but we want it very badly.

One of these NGOs also ran community sensitisation meetings and intervened in situations where individuals were being discriminated against by their family or the local community. Several respondents noted this was a sensitive issue. If they said that the community sensitisation meetings were about HIV/AIDS nobody would attend. However if they approached the subject via blood borne infections then they were able to include it as part of a bigger programme. These meetings were also held if there was a problem in a community concerning somebody's HIV status. This, NGO noted however, that these situations were complex and in some cases the overt hostility arose more from opportunism, for example the desire of powerful factions to seize somebody's home, than from any real fear of AIDS. This observation reflects work by Parker and Aggleton (2003) on stigma. This suggests that HIV/AIDS related stigma and discrimination is related to power, inequality and exclusion. Parker and Aggleton (2203) note that '...stigma feeds upon, strengthens

and reproduces existing inequalities of class, race, gender and sexuality' (Parker & Aggleton 2003: 13).

7.6 Enabling and Constraining Factors

7.6.1 Introduction

The situation described thus far reflects a number of interrelated issues, notably the inability or reluctance of many NGOs to recognise that care and support were issues that might affect some of their project users. This corresponded with the low priority afforded to care and support at the state level. There was also an underlying belief that, once somebody became infected, little if anything could be done to improve the quality of life of those affected. There was a pressing need for these assumptions to be challenged, and for examples to be provided of the positive outcomes that can be achieved despite the lack of a cure and the relative inaccessibility of ART. Where NGOs were working on providing care and support, progress had been hampered by factors such as access to funding, insufficient input by appropriately trained and skilled health workers and an inability to liaise effectively with other agencies. This section looks at factors that have enabled or constrained the NGOs working in this area.

7.6.2 Professionalism

A significant problem affecting the development of care and support concerned the skills and professional status of staff employed within the NGOs. The NGOs principally concerned with prevention and control activities largely employed graduates from the social sciences, including sociology and psychology. This meant that they had not necessarily received any formal training in counselling, although this was one of their duties. Although a number of organizations had actively addressed this issue through in-house training programmes and by participating in workshops, 'counselling' was a term widely used and it appears equally widely misunderstood. In particular the view that anybody could do counselling and that it did not necessitate any training was expressed by a number of respondents. This issue highlights the manner in which seemingly straightforward and easily understood terms can become stripped of their meaning when placed within a different context. In this case there is no direct equivalent for the word 'counselling' in Bengali. In translation, the phrase advice giving was sometimes used as the closest approximation (interview data).

Another issue around professionalism involves the role that NGOs were expected to fulfil in the delivery of community based care and support in the absence of sufficient expertise or experience. While all of the NGOs employed doctors to work in their STD clinics, other roles were carried out by staff without any formal training in health care. As such the NGOs in the study largely expected social workers and psychology graduates to undertake the planning of care and the teaching of relatives to provide this care despite having had no formal training and little or no supervised experience. Given this, it is perhaps unsurprising that the home extension team

described in section 7.3.6 provided counselling and advice on hygiene and nutrition but was unable to help with the planning of nursing care.

Qualified nurses have an important role to play in the assessment of needs and the planning and evaluation of care (Reghunath 1997). While they may not, indeed cannot, provide this care themselves due to lack of numbers, they should play a pivotal role in identifying need and liaising between different agencies and support services. They can also provide a resource when the primary carer is unable to determine what to do for an individual whose condition is deteriorating and whether or not to seek medical intervention. It is difficult to see how patients with complex needs can be effectively cared for in the absence of anybody with relevant clinical experience. One respondent commented on this saying:

If your staff are community workers they can't understand the medical side. The counselling is seen as very important but not the medical. Other NGOs have psychological or social input but very little medical care actually.

The ability to assess complex care needs and understand potential as well as actual problems demands skill and expertise which social workers are unlikely to have.

7.6.3 Funding

The problem of securing funding was the primary problem identified by NGOs who were providing care and support services. Respondents noted that that they had had difficulty accessing funding for care and support. This was understood to be because the priority of donors was awareness and prevention. This position was supported by a representative for UNAIDS who was unequivocal that the overall orientation towards prevention and control has taken precedence and that there has been a lack of awareness about the need for care and support. The director of the State AIDS

Society also stated that HIV related illnesses were very rare in West Bengal. Thus there was little need to develop care and support services because essentially there was '...no pressure ...no urgency'. However the State AIDS Society was developing its own strategies for care and support and these did not include a significant role for NGOs.

For example, one NGO had wanted to establish a hospice. Despite NACO's recognition that more hospices were needed (NACO 2000) the then director of the SAS rejected this approach to care noting that '...hospices are not favoured' because '... stigmatisation will be much worse.' Nor did the SAS favour NGOs being involved in the provision of care and support. Regarding one of the NGOs providing care and support, it was said by the State AIDS Society that, while this organization had outreach workers and would help families in the community '...their patients are not to be admitted. [It] will not have hospital or nursing staff'.

When clarification of this point was sought the respondent said that the guidelines developed by the state were that all patients needing hospital admission would be cared for by the government sector 'treatment will be available to all at the level of the government hospital'. Thus patients would be nursed in what ever clinical area was most appropriate for them and that there would not be designated AIDS wards. This point was made despite the existence of an 'AIDS ward' in Calcutta Medical College Hospital.

This had a number of implications for the NGOs in West Bengal working on HIV/AIDS. First, those NGOs not working on care and support were unlikely to be galvanised into action by the State AIDS Society. Second, the NGOs working in this area were unlikely to find it helpful and supportive with respect to funding, technical assistance and creating links with state sector care providers. This last point has

other issues associated with it. NACP2 made provision for TB medication and drugs for the treatment of opportunistic infections to be available from government hospitals (NACO 2000). However, as has been repeatedly noted, there is a significant problem for many people to access these services. At the time of the study there was a national TB programme but it was also a vertical programme and there had not been any connections created in West Bengal between the SAS and the TB programme (interview data).

While it is easy to be critical of the SAS for failing to engage with and support the NGO community, there are significant issues around the professionalism and experience within NGOs. A key weakness of NGOs in the provision of care *per se* was their ability to scale up and coverage was at best patchy. It may well not be cost effective to carry out significant training and duplication of infrastructure and supplies/equipment if, in real terms, very few people will be helped by NGOs. The money may be more effective if spent in the public sector. Of course, this again raises questions of equity and access. If NGOs do not offer care and support how are the marginalized high risk groups going to access it from the formal sector in the prevailing climate?

7.6.4 Inter-organizational collaboration

It is evident from the experiences of NGOs in the study that working in isolation from other health service deliverers had created its own problems. For example, some of the activities undertaken by NGOs had arisen because of the difficulties project users have experienced in accessing health care from both the public and the private sector. Further, when NGOs have moved towards providing clinical services they have faced problems with identifying funding sources and it appears that a break was being applied at the state level.

The need for appropriately trained workers within NGOs also raises the issue of the need for collaboration and cooperation between different health care providers. This was acknowledged by a World Bank representative working on HIV/AIDS policy at the national level in India. He noted that one strategy for providing care includes the training of NGO staff and developing their links with nurse and doctor facilities and that 'there is a need to develop models now before the problem escalates'. However he was also candid about the fact that it was difficult to see how this was going to work in practice.

Judging by the experiences and perceptions of the NGOs in the study (both those involved in providing care and support and those that were not) this was an area that still required a lot of work. There was a prevailing belief, based upon experience, that project users who attempted to access the government health care system would either be turned away or would receive inadequate or discriminatory treatment. While some attempts had been made to forge links with the private sector, for example identifying a nursing home willing to admit HIV positive patients, this option was simply not financially viable for the majority of project users. Their only hope of obtaining drugs to treat opportunistic infections lay with accessing drugs from the budget provided from the State AIDS Society and this in turn meant getting treatment from a government hospital.

7.7 Discussion

Previous chapters have discussed the nature of relationships between NGOs taking part in the study and other organizations at the state, national and international level. It was suggested that these relationships were potentially problematic. This was undoubtedly the case regarding NGO efforts to provide care and support services

where they seemed to face an almost blanket resistance. Central to this thesis is the question of what role NGOs were expected to play in the development and implementation of HIV/AIDS related policies. At the international level, stress was placed upon the ability of NGO's to identify those in need of care and support, to take an active role in providing these services and to advocate for them particularly with regard to the maintenance of human rights (United Nations 1996; World Bank 1999a). However the experience of NGOs working in West Bengal suggests that they were unable to address these issues in any substantive way. There was a lack of awareness amongst NGOs about the need for care and support or what their role in this might be. The NGOs simply did not know of people who might require these services. Further there was insufficient recognition of the lack of knowledge and expertise at this level. Although a safety net was provided by a small number of NGOs the factors that constrain service delivery such as a lack of funding and trained personnel in the state sector were replicated at the NGO level. NGOs were not picking up on the problem because they did not have experience and expertise to do so, but that did not mean that the problem itself did not exist. An additional constraint was the unwillingness of the SAS to engage with NGOs on this level. Clearly the NGOs themselves lacked the power to push these issues. Similarly there seemed to be a lack of awareness about the potential to advocate for better access to government health services, nor was there any activism around the availability of ART.

This situation was further complicated by the fact that many of the people involved in the study at the NGO level viewed the provision of care and support for socially marginalized and poor people as a fundamentally hopeless cause. The belief that nothing could be done for somebody once they were infected prevailed. This was

not helped by the fact that so few of the NGOs actually knew of any people living with HIV/AIDS. There was an almost total lack of advocacy at this level and, as has been pointed out, representation for HIV positive individuals, by HIV positive individuals, was virtually non-existent.

In consequence, at the time of the study, there was a widespread failure to put a human face to the epidemic in West Bengal. This could only serve to compound the isolation felt by those who knew or suspected themselves to be HIV positive. This invisibility made it difficult to challenge the SAS when it asserted that the occurrence of AIDS related illness was very low in West Bengal. Clearly this invisibility could be interpreted as fulfilling a protective function. Given the suspicion and mistrust expressed at the NGO level for the state sector it is not surprising that they wished to protect their project users from coming under its gaze. However the failure of NGOs to identify a need for care and support amongst their project users was also used to reinforce the claim that people were not developing HIV/AIDS related illnesses.

Chapter 8

Discussion & Recommendations

8.1 Introduction

This final chapter provides a conclusion to the study. The aim of this research was to explore the language and discourses of HIV/AIDS circulating at different levels of the policy process in India during the early years of the pandemic with a particular focus upon the work of Non-Governmental Organizations in Kolkata, West Bengal. The study found considerable differences between the participating NGOs with respect to their size, location, sources of funding, overall aims, underlying ethos and area of expertise. As such they could be seen to be unique organizations bringing diverse experiences and perspectives to bear on a problem (HIV/AIDS) that is itself, socially constructed, symbolically inscribed and has multiple meanings. Against this background, Section 8.2 will begin by discussing the studies substantive and theoretical contribution to new knowledge. Section 8.3 will provide a summary of the research findings. Section 8.4 will consider the strengths and limitations of the study methodology including reflexivity and the researcher's role. The final section 8.5 considers the implications of the study for further policy development.

8.2 Contribution to new knowledge

The thesis makes a substantive and a theoretical contribution to new knowledge in four distinct but overlapping areas. First, the study contributes to knowledge about the transfer and translation of policies for HIV/AIDS prevention and control, from the global level to the national level in India, and thence to the state level in West Bengal and finally the NGO level in Kolkata. Traditional approaches to health

policy have focused on policy content (Walt & Gilson 1994) and health policy analysis has traditionally conceptualise the policy process as rational and linear (Hogwood & Gunn 1984, Lee & Mills 1982). These approaches fails to engage with the context, actors and processes involved in the design and implementation of health policy (Walt & Gilson 1994). In recent years there has been growing academic interest in the transfer and translation of policies for public health and infectious disease control, from the global to the national and sub-national levels. This reflects the need to better understand the manner in which these policies are taken up at the global level and packaged as 'best practice', introduced into a new context, and then made meaningful at the local level (Lush et al 2003). However, there are still few examples of health policy transfer and translation between the international and national levels in the published literature. Nor is there much literature concerning the links between NGOs and communities, and the transfer of these infectious disease policies (Lush et al 2003, Ogden et al 2003). Further Seckin (2008) looking at the African context suggests that studies on HIV/AIDS tend to focus on its spread, or on the evaluation of prevention programmes. He identifies a gap in the literature concerning the mechanisms through which policies are designed and implemented. It is my assertion that a similar gap exists in the literature concerning the transfer and translation of HIV/AIDS policies from the global level to the local levels in India. This study therefore makes a substantive contribution to knowledge in this area.

Second, this study contributes to an emerging body of literature that explores new ways of theorising the term Non-Governmental Organization, in order to better understand the roles that NGOs play in the policy process. This reflects a need to critically assess some of the claims made for NGOs and to engage with the

contextual and organizational relationships within which their practices are situated (Hilhorst 2003). Boas and Mc Neill (2003) argue that ‘...[NGOs] should be viewed with the same sort of engaged criticism as that which we direct towards multilateral institution...’ (Boas & Mc Neill 2003: 135). Against this background the study explored two interrelated themes in the published literature.

The first theme concerns the term ‘NGO’. Hilhorst (2003) argues that NGOs are commonly understood to be organizations that ‘do good’ for the development of others, and as such ‘NGO’ is a claim-bearing label (Hilhorst 2003:7). This perception of NGOs comes through very strongly in the global guidelines for HIV/AIDS prevention (United Nations 1996, World Bank 1999, DFID 2003, UNAIDS no date). However, this view of NGOs is not universally accepted. This research explored whether, within the context of West Bengal, this view was contested, and if so what the implications were for the translation of policy. Second, the literature also suggests that NGOs are better understood as fragmented sites (Mageli 2005), ‘...not things, but open ended processes’ (Hilhorst 2003:3). This reflects the fact that hegemonic approaches to development discourse have been discredited and it is increasingly recognised that there are a multiplicity of voices in development, both within and across institutions and organizations (Boas & McNeill 2003). Therefore the work of NGOs needs to be understood within the socio-economic and cultural context that it takes place (Seckinelgin 2008: 70). This involves exploring their relations with other actors and recognising the fluid nature of these relationships (Mageli 2005). This study included an exploration of the multiple, overlapping relationships between NGOs and other organizations, and individuals, involved in HIV/AIDS policy. As such the study contributes to an understanding of NGOs as fragmented sites with permeable boundaries, rather than

as monolithic wholes, and as sites of contested meaning, and therefore advances theoretical knowledge.

Third, the study contributes to knowledge about the different discourses of HIV/AIDS in circulation in India, and West Bengal, and the ways in which these inform and engage with approaches to prevention and control and care and support. With the exception of a small number of published studies this is an under explored area (see for example Karnik 2001, Moody & Sarani 2005, Finn & Sarangi 2008). The research draws upon a wide body of literature, including the literature surrounding nationalisms and sexualities, colonial and post-colonial discourses and political approaches to the symbolic construction of nation-statehood. It develops the discursive links between ideas of globalization and the nation-state, and representations of risk and vulnerability in HIV/AIDS policy at the national, state and NGO levels. In doing this it makes a substantive contribution to new knowledge

Fourth, the study offers a substantive contribution to knowledge regarding the incorporation of reflexivity into the research process and the researcher/nurse divide. Health Policy is an interdisciplinary field, and whilst a background in health care may be helpful it can also be problematic if the researcher is unable to reflect upon their own position within the research (Arber 2006). Therefore, it is important to understand how the identity of the researcher can affect the research process. This research provides a detailed account of the manner in which the inter-subjectivity of the researcher and the dual role of researcher/nurse was implicated at all stages of the research process. As such it offers a substantive contribution to knowledge in this area.

8.3 Summary of main research findings

8.3.1 Discourses of risk and vulnerability

At the national level HIV/AIDS was constructed as a foreign disease and subsequently as a disease of deviancy. HIV/AIDS was understood to be a Western disease caused by Western lifestyles, one that a chaste India would not be affected by. Thus to be infected with HIV was to be un-Indian. The suggestion from international actors, that India might be on the precipice of a devastating epidemic, was interpreted by some within India as an orientalist discourse arising from Western beliefs about disease and deviancy and as such it was strongly resisted. The identification of risk groups in India engaged with these understandings, thus there was a focus upon groups with pre-existing stigma such as sex workers and truck drivers. Over time, further groups were added with poverty and migration also becoming key indicators of perceived risk. Although there was evidence to suggest that the 'general' population was also at risk of infection this was over looked in favour of the development of a targeted approach to prevention focusing on high risk groups.

The development of HIV/AIDS policy within India was a controversial issue at the time of the study. NACPI, and subsequently NACP2, was believed by many, within India, to have been imposed by the World Bank. Further it was argued that policies promoted approaches to prevention and control that were culturally inappropriate. HIV/AIDS was also understood to be emblematic of the process of globalization, one that represented a threat to Indian security and national identity. Post-colonial discourses of the nation state, and the symbolic inscription of women's bodies to represent a 'pure' India, overlapped with these ideas of HIV/AIDS as a potent threat

to the nation state. At the policy level representations of monogamy and promiscuity intersected with existing discourses of purity and defilement. These policies also distinguished between risk groups and the 'general public' despite emerging infection in groups reputed to be at low risk such as women attendees at ante- natal clinics.

At the level of the state in West Bengal, HIV/AIDS continued to be understood as a disease of others. The un-Indian designation was distilled further and HIV/AIDS was constructed as an un-Bengali epidemic. During the time frame of the study there was no clear evidence about the nature or extent of HIV/AIDS in the state. Policy makers suggested that it was not a real problem, with infection associated with marginal groups only. This position was however, challenged by some doctors who suggested that a generalised epidemic had already developed. Notwithstanding this policy development was slow during the time frame of the study and discourses of deviancy and poverty dominated understandings of the problem.

8.3.2 Implications for prevention and control and care and support

The NGOs in the study understood risk and vulnerability as arising from a range of contextual factors linked to poverty, inequalities and pre-existing stigma. These conformed to a development model. The study found that consequently some of the NGOs questioned the appropriateness of prevention and control interventions that were premised upon biomedical and behavioural strategies. These, it was argued, failed to engage with the realities of people's lives, and the structural factors that constrained their life choices. For other NGOs this assimilation was less problematic and they espoused the targeted intervention approach with varying degrees of enthusiasm. However, it became clear in the course of the study that NGOs, irrespective of whether they had adopted a targeted intervention approach or not,

were also offering a wide range of welfare orientated services. The capacity of NGOs to do this depended upon their source of funding and the willingness of donors to think more broadly about what HIV prevention work entailed, or to simply prioritise the priorities of NGOs over their own funding priorities. For example one NGO had been able to focus on a flood relief programme following severe monsoon flooding. However, for the majority of NGOs funding was an ongoing problem and there were few situations where the priorities of NGOs actually over rode donor priorities.

Linked to this was the issue of whether NGOs were able to feed back into the policy process. There was a widespread belief that the contextual, holistic, social welfare aspects to their work were being over-looked thus contributing to a lack of understanding at other levels of the policy process, about the reality and complexity of their work, as opposed to the aspects of it captured in project monitoring activities. Thus they faced the problem of how to contribute to the policy debate and how to influence funding priorities.

The question of care and support also raised a number of issues. In this case a key stumbling block was that of the absence of people living with HIV/AIDS from projects. This is significant because one aspect of NGO legitimacy was premised upon their advocacy role and their ability to take the views and needs of HIV positive individuals into the policy arena. Another issue was the lack of experience of providing care and support within NGOs. This was compounded by the reluctance of the SAS to support NGOs in providing care and support services. The issue of state/NGO relationships will be returned to below. First however, it is important to reiterate that NACO policies ruled out the provision of ART and highlighted the need for home-based care and support. This was consistent with the World Bank's

position on the targeting of scarce resources. However this also dovetailed with some understandings of the epidemic within India. HIV/AIDS was understood to be one health problem amongst many. There was a realization that, for many people, health care was inaccessible and that prior to HIV/AIDS there was already a lack of provision and access to health services for poorer sections of society.

8.3.3 Relationships within the policy process

NGO/State relations within West Bengal were extremely strained during the time frame of the study and respondents reported numerous ways in which their work had been impeded by the SAS. Despite the rhetoric of inclusive policy-making, NGOs had limited dealings with the SAC/SAS. The WBSHP had, in effect, developed in the place of a state level response to the development of targeted interventions. During the time frame of the study NACO policies treated the role and involvement of NGOs in a relatively uncritical manner. Changes in policy from NACPI to NACP2 - for example the creation of State AIDS Societies - recognised that NGO/state relations were a major stumbling-block to policy implementation within some states. However, this was presented as a relatively straightforward design problem (NACO 2000). In reality, NGOs were relatively powerless in their dealings with the SAS. Thus, despite the rhetoric, the response of the SAS was largely hostile. This suggests that within the SAS, the idea of NGOs as organizations that do good for the development of others, was not commonly accepted. This evidently had implications for policy development.

This discussion illustrates the complex web of relationships that existed between NGOs and other policy actors and institutions (both nationally and at the State level). This suggests that policies need to be sensitive to the individual and unique characteristic of NGOs. In reality, NGOs are frequently conceived of as a

homogeneous group (Mageli 2005). Definitions attempt to identify unifying characteristics and themes when in fact it can be argued that no two NGOs are alike (Smillie 1999). In reality, NGOs may be better understood as 'fragmented sites' that occupy a universe that is 'blurred, shifting, unstable and in constant development' (Mageli, 2005: 265). The implications of this for policy development will be discussed in section 8.4.

8.4 Strengths and limitations of the study methodology

The study methodology offered a good match between the analytic framework and the approach taken to data collection and analysis. Walt and Gilson's (1994) framework, and subsequent work on policy transfer and policy translation engages with an understanding of the policy process as one with multiple actors and multiple levels. There is a need to recognise differences of approach and orientation within the policy process. It also recognises that there can be differences in perspective and understanding within organizations. The framework for analysis provided a means of identifying the actors, processes and contexts involved in HIV/AIDS policy and programming, and of conceptualising the policy process prior to the collection and analysis of data. The theory upon which discourse analytic research is based, proposes that knowledge is time and context specific, and that meaning is created within distinct language communities. The approach to research following from this, is one that is concerned with identifying these multiple voices and subject positions. By combining Walt and Gilson's (1994) analytic framework with Carabine's approach to discourse analysis I was able to first, identify the multiple actors and organizations within the policy process and the contextual factors influencing them, and second, collect and analyze the data in a way that was responsive to differences and multiple perspectives.

Further, Walt (1994) identifies the importance of the operation of power within the policy process. She argues that rationale top down, or bottom up, linear models fail to adequately account for the manner in which power circulates within the policy process. By adopting a genealogical approach to the research, power was conceptualised as something that was diffuse and circulated at all levels of the policy process. Linked to this, the study methodology enabled me to look at the different ways in which the problem of HIV/AIDS was constructed, and the discourses of risk and vulnerability associated with these different constructions, and thus to explore the implications of these for policy development and implementation.

The study involved two stages of field-work and these enabled me to follow through the process of the hand over from the WBSHP to the SAS. During the second field trip respondents were more willing to talk about the difficulties that they had encountered during this process. There seemed to be, at times, a sense that respondents were using the opportunity of talking to me to reflect upon their own experiences, understandings and perspectives on the project. In this manner I felt that I was incorporated into the narratives that they were constructing about the events of the previous few months. I also felt less constrained during this second phase of field work, and was more willing to ask questions of respondents, than I had been in the first phase if I felt then to be sensitive. For example I discussed my feelings about SHIP, at length, with the former director of the WBSHP, something that I had felt unable to do, on ethical grounds, whilst the relationship between the two organizations had been a formal one. This concerned my own ambivalent feeling about their campaign for the legalization of sex work.

Briefly, on the one hand I felt that it was important to respect and recognize their agency in this issue. On the other, I didn't really believe claims that the quality of

the sex workers' lives had improved materially. I found the project staff to be unhelpful and I was really uncomfortable about the manner in which they pressed me for money prior to granting interviews. But I also felt that they had a legitimate right to ask for money, why should they give of their time for nothing? This expectation could be read as another form of post-colonial appropriation. I have never been to reconcile these conflicting feelings. However, in writing about SHIP and their dispute with Shanlaap (see section 6.4.4) I have been, I believe, able to present their different understandings and perspectives without including my own value judgements. The process of working reflexively helped me to reach a point at which I felt able to do this.

Notwithstanding these strengths, the study methodology also had some limitations. Foremost amongst these was the fact that the research aims were very broad and the study would have been better executed if I had refined my focus, for example by looking at understandings of risk and vulnerability in the policy process, rather than the policy process as a whole. I would not undertake another piece of research with such broadly defined aims. Further the study did not include the perspective of people living with HIV/AIDS. It seems to me now that the study, could be seen to be talking *about* people living with HIV/AIDS rather than *to* them and this links uncomfortably in my mind with understandings of neo-colonial discourses of public health that fail to engage fully with, or recognize the subjectivity of, the people being studied. In this instance the primary focus was on NGOs and there were valid reasons for not incorporating the perspectives of project users into the research design (see page 97 for a discussion of these). If I were to undertake further study in this field I would want to look at the inter-relationships between actors within a

given NGO, the individuals using the services of that NGO, and their relationships to the broader context within which this work and their lives were situated.

I want finally, to offer some thoughts about the manner in which my own subjectivity was implicated in the research process. I have already discussed the manner in which my dual identity as nurse and researcher was implicated in aspects of the study in some detail at different points in this thesis. I think now, that my deep rooted ambivalence about my identity as a nurse, did impact upon aspects of the study, although by returning to my primary sources I have been able to untangle some of these complicated feelings, and re-analyse the study data in a more sophisticated and reflexive fashion. This dual identity, despite the discomfort that it at times caused me, also helped me to develop a degree of credibility with study respondents and opened doors for me in perhaps surprising ways so can also be seen in a positive light.

To give a final example of this, towards the end of the study I was involved in an informal, group discussion within an NGO, that I had had regular contact with. The theme was an overview of HIV/AIDS and there were a number of female employees from across the organization in attendance. The NGO's education officer led the session. The discussion was in Bengali and she translated for me. All of the women spoke in Bengali. Towards the end of the session the education officer asked me in English if I would say 'a few words about monogamy'. I was taken aback by this, because I did not know what to say, so I asked if I could think about it first. At the end of the session she returned to the question. What I said in essence was that whilst monogamy might be a desirable concept in theory, it was not in reality that straightforward. It seemed to me that it was often easier to talk about ideas in a group in the abstract, than it was to talk in concrete terms, with a sexual partner. The

education officer translated what I had said, and to my surprise several of the women responded in English.

The first woman who spoke said 'Yes, we cannot speak of these things to our husband. We are too shy and what would he think'. Another woman said that whatever a man did out of the home was his business you could not ask have you been with some other woman? It was simply not possible and you might know or suspect but you would never ask. Another woman said that 'they' tell us to be monogamous but what about our husbands? Who will tell them? We cannot. One woman then asked me if I was a nurse and when I said yes she said that they had many questions that they would like to ask me because it was so hard to get any information, and they had no one to turn to for advice.

These questions surprised me because far from being about HIV/AIDS they were about other things altogether including breast cancer and the transmission of hepatitis A and B. I have reflected on this encounter at length, initially in my research diary and then in discussion with a doctor, and a Bengali friend. It conveyed powerfully to me the fact that the women that day, had different priorities and interests to those set by the organization. As a nurse I was valuable source of information for them. Equally, I gained some important insights about the priorities and information needs of this group of women and I also began to really reflect upon what 'monogamy' meant both to them as a group of women, and more broadly how it was understood, and used as a concept, within HIV/AIDS policy.

8.5 Implications for policy

8.5.1 Introduction

This section is concerned with the implications of the study for future policy development. As such it is divided into three sections. The study suggests a number of areas about which more needs to be known in order to better inform policy makers and make clear the links between problem construction and policy responses. Therefore section 8.5.2 considers the area of research *for* policy as a means of better understanding the HIV/AIDS pandemic in West Bengal and facilitating more reflexive policy making. Section 8.5.3 looks specifically at the role of NGOs and considers ways in which their role can be better understood and supported by other actors in the policy process. Finally section 8.5.4 is concerned with the limitations of NGOs and the necessity of re-thinking some aspects of their role.

8.5.2 A better understanding of the HIV/AIDS pandemic in West Bengal

This section is premised upon the belief that further research would make a significant contribution to the quality of policy making. There remains a pressing need for a better understanding of the contours of the HIV/AIDS pandemic in West Bengal. The sentinel surveillance system has expanded since the time of the study and the Government of India's long held position that rates of infection are lower than WHO projections suggest has been accepted (UNAIDS & WHO 2007). However, the basis upon which sentinel surveillance has been carried out remains the same. In reality there has been a refinement of risk groups so that three groups, commercial sex workers, men who have sex with men and injecting drug users, are now the focus of prevention and control activities (NACO 2008). The findings of

this study suggest that this will not help to counter the way in which HIV/AIDS has been constructed as Un-Bengali and as a disease of deviance.

These discourses and the way in which they feed into policy need to be better understood. Further, work drawing upon post-colonial theory as it relates to discourses of HIV/AIDS in West Bengal (and India) would provide useful perspectives on the relationships between the Indian State (both Nationally and within West Bengal) and the global public health community. This is important given the manner in which global institutions such as UNAIDS and the World Bank are implicated in the design and funding of HIV/AIDS policy.

Allied to this is the problem of stigma and discrimination and the need for India to frame the response to HIV/AIDS within a human rights based approach. This point is raised frequently in relation to HIV/AIDS policy in India and it defies any sort of easy answer (Rajkowha 2002, Sethi 2002). The study suggests unequivocally that this is too big a problem to be left to NGOs. The study found that within the West Bengal SAS there was a belief that NGOs needed to change social attitudes in order to create a positive climate for the repeal of discriminatory legislation. This is an unhelpful position for State level institutions to adopt. The human rights agenda needs to be fully embraced and supported.

This raises a number of associated issues. First it is often argued that there is a need for a human face to be put on the pandemic. Studies of HIV/AIDS talk of a normalization of the pandemic (Rosenbroock et al 2000). I believe this to be more complex than perhaps at first appears, not least because some of the associated stigma and discrimination is opportunistic and relates to widespread pre-existing inequalities (Parker & Aggleton 2003, Priya & Sathyamala 2007). Arguably the

Indian pandemic already has a human face - it is the face of poverty and stigma - and this is part of the problem.

Further whilst awareness coupled with a poor knowledge base amongst the general public will clearly have some impact on stigma and discrimination it is not the whole story. Paul (2007) highlights an important point when he notes that educated professionals are responsible for a lot of HIV/AIDS related discrimination. This observation is particularly relevant for the health sector hence the discussion here will focus upon that sector. What is needed is for discrimination - wherever it is encountered and whatever it entails - to be countered using whatever means possible. The regulatory bodies for medicine and allied health professionals need to be involved in this. This could mean looking at the regulation of nurses and doctors and their professional practice from the perspective of broad based principles rather than within the context of a specific disease focus, for example in relation to informed consent and confidentiality. The underlying rationale for adopting universal precautions for the prevention of infection offers a good example of broad based guidelines that apply to every patient and every situation as such offer a clear benchmark for patient care (and the safety of staff)²³.

Allied to this, norms of practice within the Indian nursing and medical profession need to be better understood by other actors in the policy process at the international and global levels. Concepts such as confidentiality, informed consent and counseling need to be understood in relation to the context within which they are used. For example informed consent and confidentiality are not understood in the same way in the Indian context as they are in the UK (Personal communication Professor

²³ It is recognised that in practice there are also financial and logistic constraints to the manner in which universal precaution are maintained but the principle holds good here.

Twycross). Informed consent may be reduced to taking a signature or finger-print without ever explaining the document that is being signed (Priya 1994a). A diagnosis of cancer is frequently not conveyed to the patient, therefore he/she may undergo treatment without ever having been told why. Whilst this is not to minimize the trauma and distress caused by breaches of confidentiality, the context within which these take place need to be better understood as the first step towards better practice.

The state also has responsibility for the regulation and control of the police force. The decision in West Bengal to situate the SAS within the state police headquarters is problematic to say the least. The police need to be held to account if and when they step outside of their jurisdiction. Finally people living with HIV/AIDS need to be given a voice. This should include active representation and participation within the SAS and within NGOs that choose to work on HIV/AIDS.

8.5.3 Enhancing NGO performance and widening their sphere of influence

Opportunities for NGOs to 'frame up' or influence the policy agenda were limited during the study period. This meant that the more integrated and holistic activities that they carried out failed to be identified as part of a strategy for prevention. NGOs need to be able to contribute to international and national policy. Porter et al (2002) identify that one barrier to this has been the inability of NGOs to conduct and present research that conforms to the norms of international peer review journals:

Organizations like NGOs already conduct research in its broadest sense. For the information and data to be considered appropriate, however, and for it to be used at the international and national levels, it needs to be presented and communicated in a particular way, according to standards laid down by those in powerful positions in Euro-America.... (Porter et al 2004: 80).

A study from Brazil (Paiva et al 2002) reviewing the success of their model for HIV prevention suggests that one of the key reasons for this was consistent collaboration between civil society groups (NGOs) and government agencies. The study reported on non-degree level training for civil society actors that was intended to enable participants to evaluate and conduct research.

This study found that training courses for NGOs were often very short running over one to two days. As such they had limited potential to do much more than raise key issues. The research and training needs of NGOs should be re-evaluated. Comprehensive, non-degree level training in research of the kind described in the Brazilian study would offer NGOs a better way of engaging with the academic requirements of national, international and global public health. Universities and NGOs could work collaboratively on this. There is research expertise within the NGO community in West Bengal already and NGOs in the study were employing social science graduates. This should be built upon.

Collaboration and interagency working is another key issue shaping the potential to enhance NGO performance. The study showed very clearly that State/NGO relationships were strongly implicated in the extent to which NGOs could fulfil their remit. These relationships were often experienced as tense and uncooperative. This presents another difficulty when trying to advance policy. In particular it impacts upon the capacity of NGOs to become actively involved in care and support. However, it is not the only factor that limits this role. The majority of the NGOs in the study lacked the skills and the capacity to offer health care (except in limited ways). Therefore policies need to look again at how people living with HIV/AIDS are able to access health care and the barriers to this. Inevitably the poor and socially excluded will struggle to do this. As a starting point, care needs to be conceptualised

across a continuum (Gilkes 2001). This is especially important as ART is being introduced. The question *what care is needed?* should be asked first and then *who will provide this care?* Undoubtedly it is important to improve contact between NGOs and government health care providers. At the time of the study this was conceptualised as a problem for NGOs. However the study also found that in many cases people were presenting directly to the health sector (and did not have a relationship with the NGO sector).

In this scenario it is important to develop the mechanisms for hospitals and health care settings to refer to NGOs and not vice versa. The health care sector is a critical site for identifying and supporting individuals and the flow of information should be from the health sector to the NGO and not entirely premised upon the reverse. This is particularly the case if home-based care is envisaged. A study from Zambia of home-based care found that NGOs were limited in their capacity to provide this care because of the lack of government involvement. It also found that qualified nurses needed to be involved in care (Nsutebu et al 2001). Reghunath (1997) outlines the role for community nurses in the delivery of home based care in the Indian context and suggests a model that involves collaboration between community level nurses, NGOs, the patient and his or her family. The nurse's role is crucial in this in terms of identifying problems, planning care and providing training and support.

Against this background, it is important that some body has oversight of the different care providers, and types of care available, (community, state, private NGO etc) to assist the diagnosing agency or individual with referring on PLWHA for appropriate care. This would be effectively a case coordinator role. Positive collaboration between the NGO sector and the government sector does exist within West Bengal. For example the School of Tropical Medicine (STM) in Kolkata and an

NGO, Calcutta Rescue (CR), have developed a reciprocal arrangement where STM patients who have developed resistance to first line ART are referred to CR. These patients are provided with second line ART and in return CR patients are referred to the STM for first line treatment (Chatterjee 2006). This shows what is possible if people are willing to collaborate.

8.5.4 The limitations of NGOs and the necessity of re-thinking some aspects of their role.

Finally, there needs to be a sense of realism about what NGOs can achieve on their own in a less than receptive climate. NGOs should not be expected to achieve what the state has failed to deliver. Clearly NGOs cannot tackle the human rights aspects of HIV/AIDS alone. Nor are they equipped to deliver health services without considerable support and the active involvement of other agencies. Some areas such as prison work may need to be re-thought, or at the very least for interventions to be initiated within the prison by the prison authorities with a mechanism for referral to the NGO sector if the individuals gives consent for this to happen. It is also important to recognise the individuality of the sector. The expectation that all NGOs will be competent in all aspects of HIV/AIDS related work is unrealistic. Each NGO will have its strengths and weaknesses. Case studies of NGOs would provide the opportunity to better understand their strengths and weaknesses.

8.6 Conclusion

This study found that the dominant paradigm of targeted interventions in West Bengal (as exemplified by the WBSHP model) obscured the more holistic and integrated approach that several of the local NGOs took to working with vulnerable groups. As such, there was a problem with 'framing' the interventions to reflect all aspects of NGO work rather than the aspects that fit with donor objectives. Conceptually, the emphasis placed by national and international policy actors on targeted interventions with risk groups was problematic, because it contributed to the stigma and discrimination experienced by some vulnerable groups. This was exacerbated by the lack of a state level response to the human rights dimension of the pandemic. Further NGO/State relationships were strained which impacted upon the development of NGO based services.

Given these constraints, policies need to be realistic in the role that is designated for NGOs within West Bengal and should consider other ways of reaching vulnerable groups and developing services. The state also needs to engage more fully with the human rights agenda. The implied homogeneity of NGOs in policies is also problematic. It might be more useful to view NGOs as fragmented sites characterized by diversity and difference. This would allow individual NGOs to play to their strengths. It might also temper a sense of realism about the part that NGOs can play in the design and implementation of HIV/AIDS related policies and programming.

References

- Altheide, D.L. & Johnson, J.M. (1994). Criteria for Assessing Interpretive Validity in Qualitative Research. pp 485-499 in Denzin, N.K. & Lincoln, Y.S. (eds) *Handbook of Qualitative Research*. London, New Delhi, Thousand Oaks, Sage Publications.
- Anon. (1996). Global Overview: A powerful HIV/AIDS Pandemic. pp 5-40 in Mann, J.M. & Tarantola, D.J.M. (eds) *AIDS in the World II. Global Dimensions, Social Roots, and Responses*. New York, Oxford, Oxford University Press.
- Antia, N. H. & Mistry, N. (1998). Women in Panchayati Raj: Implications for Health for All. pp 126-130 in Mukhopadhyay, S. (ed) *Women's Health, Public Policy and Community Action*. New Delhi, Manohar Publishers.
- Apthorpe, R. (1997). Writing development policy and policy analysis plain or clear. On Language, genre and power. pp 43-58 in Shore, C. & Wright, S. (eds) *Anthropology of Policy. Critical Perspectives on Governance and Power*. London, New York, Routledge.
- Arber, A. (2006). Reflexivity: a challenge for the researcher as practitioner? *Journal of Research in Nursing*. 11: 147-157.
- Arksey, H. & Knight, P. (1999). *Interviewing for Social Scientists*. London, Thousand Oaks, New Delhi, Sage Publications.
- Arnold, D. (1993). *Colonizing the Body. State Medicine & Epidemic Disease in Nineteenth Century India*. Berkeley, Los Angeles, London, University of California Press.
- Arnold, D. (1997). Sex, State, and Society: Sexually Transmitted Diseases and HIV/AIDS in Modern India. pp 19-36 in Lewis, M. & Bamber, S. (eds) *Sex, Disease & Society: A Comparative History of Sexually Transmitted Diseases and HIV/AIDS in Asia and the Pacific*. Westport Connecticut & London, Greenwood Press.
- Asthana, S. (1996). Aids-related policies, legislation and programme implementation in India. *Health Policy & Planning* 11(2): 184-197.
- Asthana, S. & Oostvogels, R. (1996). Community participation in HIV prevention: problems and prospects for community-based strategies among female sex workers in Madras. *Social Science and Medicine* 43(2): 133-148.

- Atlas, T. (2005). A hidden scourge. *US News and World Report*. 139(3): 52-54.
- Author unknown. (2004). Abating or exploding? *Economist*. 371(8371): 21-2.
<http://web.ebscohost.com/ehost/delivery?vid=4&hid=4&hid=17&sid=f41cf6c-e129-4829-aa> [date accessed 28/06/08].
- Author unknown. (2007). Not half as bad. The latest estimates suggest HIV is less prevalent in India than was feared. *Economist*. 384(8538): 42-43.
<http://web.ebscohost.com/ehost/delivery?vid=4&hid=116&sid=36ee8a26-a792-476c->
 [date accessed 28/06/08].
- Aviles, L.A. (2001). Epidemiology as discourse: the politics of development institutions in the Epidemiological Profile of El Salvador. *Journal of Epidemiology and Community Health* 55: 164-171.
- Bahree, M. & Stewart, E. (2008). Caveat Donor. *Forbes* 181(4): 77-77.
- Bailey, C. A. (1996). *A Guide to Field Research*. Thousand Oaks, London, New Delhi, Pine Forge Press.
- Balhatchet, K. (1980). *Race, Sex and Class under the Raj: Imperial Attitudes and Policies and Their Critics 1793-1905*. London, Weidenfeld & Nicolson.
- Balk, D. & Lahiri, S. (1997). Awareness and Knowledge of AIDS Among Indian Women: Evidence From 13 States. *Health Transition Review* 7 (supplement): 421-465.
- Ballinger, C. (2003). Navigating Multiple Research Identities. Reflexivity in Discourse Analytic Research. pp 66-77 in Finlay, L & Gough, B. *Reflexivity a Practical Guide for Researchers in Health and Social Science*. Oxford UK, Malden USA, Carlton Australia, Blackwell Publishing.
- Banerjee, A. (ed). (2001). *Millennium Mila Mela*. Kolkata, Durbar Mahila Samanwaya Committee in collaboration with DFID, UK Bharati Dey Publishers.
- Banerjee, U. (2005). Progress in Diagnosis of Opportunistic Infections in HIV/AIDS. *Indian Journal of Medical Research* 121: 395-406.
- Banerji, D. (1993). Simplistic Approach to Health Policy Analysis: World Bank Team on Indian Health Sector. *Economic & Political Weekly* 12th June: 1207-1210.

- Banerji, D. (1999). A fundamental shift in the approach to international health by WHO, UNICEF and the World Bank: Instances of the practice of 'intellectual fascism' and totalitarianism in some Asian countries. *International Journal of Health Services* 29 (2): 227-259.
- Barnett, T. & Whiteside, A. (2002). *AIDS in the Twenty-First Century. Disease and Globalization*. Basingstoke, New York, Palgrave Macmillan.
- Baru, R. & Jessani, A. (2000). The role of the World Bank in international health: renewed commitment and partnership. *Social Science & Medicine* 50: 183-184.
- Basu, A. & Dutta, M.J. (2008). Participatory Change in a Campaign Led by Sex Workers: Connecting Resistance to Action Orientated Agency. *Qualitative Health Research* 18(1): 106-119.
- Bayley, A.C. (1984). Aggressive Kaposi's Sarcoma in Zambia. *Lancet* 1: 1318-20.
- Bhatt, C. (2003). The Land, The Blood and the Passion: the Hindu Far-Right. pp195-203 in Weeks, J., Holland, J. & Waites, M. (eds) *Sexualities and Society. A Reader*. Cambridge, Oxford, Maldon, Polity.
- Bhatt, R. (1993). The private/public mix in health care in India. *Health Policy & Planning*. 8(1): 43-56.
- Bhatt, R. (1999). Characteristics of private medical practice in India: a provider perspective. *Health Policy & Planning*. 14(1): 26-37.
- Burlet, S. (1999). Gender relations, 'Hindu' nationalism, and NGO responses in India. *Gender and Development* 7(1): 40-47.
- Berkley, S. (1997). The International AIDS Vaccine Initiative. *Journal of the International Association of Physicians in AIDS Care* 11: 30-34.
- Bharat, S. (1999). *HIV/AIDS Related Discrimination, Stigmatisation and Denial in India- a Study in Mumbai and Bangalore*. Mumbai, India, Tata Institute of Social Sciences.
- Bharat, S. & Aggleton, P. (2002). Community Responses to HIV/AIDS in Mumbai City. pp 91-111 in Panda, S., Chatterjee, A. & Abdul-Quader, A.S. (eds) *Living With The*

AIDS Virus: The Epidemic and the Response in India. New Delhi, Thousand Oaks, London. Sage Publications.

Bhattacharyya, H. (2002). *Making Local Democracy Work in India: Social Capital, Politics and Governance in West Bengal*. Calcutta, India, Vedams.

Bhoruka Public Welfare Trust (2000). *Annual Report 2000*. Kolkata, India. Unpublished.

Bhoruka Public Welfare Trust. (No Date). *Looking Ahead Positively*. Kolkata. India. Unpublished.

Black, M. (1992). *A Cause for our Times. Oxfam the first 50 years*. Oxford, Oxfam.

Boas, M. & McNeill, D. (2003). *Multilateral Institutions. A critical Introduction*. London, Stirling, Virginia, Pluto Press.

Bollinger, R. C., Tripathy, S.P. & Quinn, T.C. (1995). The human immunodeficiency virus epidemic in India: Current magnitude and future projections. *Medicine*. 71(2): 97-106.

Bonell, C. & Imrie, J. (2001). Behavioural interventions to prevent HIV infection: rapid evolution, increasing rigour, moderate success. *British Medical Bulletin* 58: 155-170.

Boyce, P. (2006). Moral ambivalence and irregular practices: contextualizing male-to-male sexualities in Calcutta/India. *Feminist Review*. 83: 79-98.

Boyce, P., Huang Soo Lee, M., Jenkins, C., Mohamed, S., Overs., C, Palva, V., Reid, E., Tan, M. & Aggleton, P. (2007). Putting sexuality (back) into HIV/AIDS: Issues, theory and practice'. *Global Public Health* 2(1): 1-34.

Brewer, J. & Hunter, A. (1989). *Multimethod Research: A Synthesis of Style*. Sage Publications, London & New Delhi.

Bryman, A. (2008.) *Social Research Methods*. 3e Oxford, Oxford University Press.

Buse, K. & Walt, G. (2000). Role Conflict? The World Bank and the World's Health. *Social Science and Medicine* 50: 177-179.

Buse, K., Mays, N. & Walt, G. (2005). *Making Health Policy*. Berkshire, England, Open University Press.

- Cannon, C. (2000). NGOs and the State: a case-study from Uganda. pp 109-123 in Pearce, J. (ed) *Development, NGOs and Civil Society*. Oxford, Oxfam UK.
- Carabine, J. (2001). Unmarried Motherhood 1830-1990: A Genealogical Analysis. pp 267-310 in Wetherell, M., Taylor, S. & Yates, S. (eds) *Discourse As Data. A Guide for Analysis*. London, Thousand Oaks, New Delhi, Sage.
- Caravano, K. (1991). More than mothers and whores: redefining the AIDS prevention needs of women. *International Journal of Health Services* 21(1): 131-42.
- Chauhan, B. (1998). Family Disowns HIV Patient. Blood transfusion leaves man without job, home. *Asian Age*. 2nd December 1998.
- Chacko, E. (2004). Positionality and praxis: fieldwork experiences in rural India. *Singapor Journal of Tropical Medicine*. 25(1): 51063.
- Chandrasekaran, P., Dallabetta, G., Loo, V., Rao, S., Gayle, H., & Alexander, A. (2006). Containing HIV/AIDS in India: the unfinished agenda. *The Lancet Infectious Diseases* 6:508-21.
- Chatterjee, A., Kumar, S .K. & Abdul-Quader, A.S. (2002). Targeted Interventions in Injecting Drug Users: Some Experiences. pp 130-149 in Panda, S, Chatterjee, A. & Abdul-Quader, A.S.(eds) *Living with the AIDS Virus. The Epidemic and the Response in India*. New Delhi, Thousand Oaks, London.
- Chatterjee, A. & Sahgal, K. (2002). HIV awareness and control: the role of Non-governmental Organizations in the country. pp 62-76 in Panda, S., Chatterjee, A. & Abdul-Quader, A.S. (eds) *Living with the AIDS Virus: The Epidemic and the Response in India*. New Delhi, Thousand Oaks, London. Sage Publications.
- Chatterjee, P. (2006). AIDS in India: police powers and public health. *The Lancet* 367, 805-806.
- Chatterjee, P. (1997). *The Nation and its Fragments. Colonial and Post Colonial Histories*. Delhi, Calcutta, Chennai, Mumbai, Oxford University Press.
- Chatterjee, S. Hope Pill: Free Drugs for AIDS Patients. *Times Of India* 15 May [online].Available:
<http://epaper.timesofindia.com/APD26302/Printart.asp?skinfolder=TOIKM&banner>
 [date accessed: 15/05/06].

- Chattopadhyay, D. & Banerjee, F. (1998). Hoogley Panics after three AIDS Deaths. *Asian Age*. 16th October 1998.
- Clark, J. (1991). *Democratizing Development: The Role of Voluntary Organizations*. London, Earthscan Publications Limited.
- Clarke, G. (1998). Non-Governmental Organizations (NGOs) and Politics in the Developing World. *Political Studies* XLVI: 36-52.
- Coates, T.J., Aggleton, P., Gutzwiller, F., Des Jarlais, D., Kihara, M., Kippax, S., Schechter, M. & van den Hoek, J.A.R (1996). HIV prevention in developing countries. *The Lancet*. 348: 1143-1148.
- Coates, T.J., Richter, L. & Caceres, C. (2008). Behavioural strategies to reduce HIV transmission: how to make them work better. *The Lancet*. 372: 699-684.
- Cowley, G. & Mazumdar, S. (2002). A Deadly Passage to India. *Newsweek* 140(22): 1-6 <http://web.ebscohost.com/ehost/delivery?vid=4&hid=13&sid=cabfbdf2-5ede-412c-97> [date accessed: 28/06/08].
- Das, V. (1995). *Critical Events. An Anthropological Perspective on Contemporary India*. Delhi, Bombay, Calcutta, Madras, Oxford University Press.
- D' Cruz, P. (2003). *In Sickness and in Health: The family Experience of HIV/AIDS in India*. Kolkata, India, Stree.
- Danziger, R. (1994). The Social Impact of HIV/AIDS in Developing Countries. *Social Science & Medicine* 39(7): 905-917.
- Das, R. (2008). State identity and representations of danger: competing world views on Indian nuclearisation. *Commonwealth and Comparative Politics*. 46(1): 2-28.
- Das, T. (2009). The information and financial power of the World Bank: knowledge production through UN collaboration. *Progress in Development Studies*. 9(3): 209-24.
- Dasgupta, P.R., Jain, M.K. & John, T.J. (1994). Government response to HIV/AIDS in India. *AIDS* 8(supplement 2): 83-80.
- Das Gupta, M. (1995). Life Course Perspectives on Women's Autonomy and Health Outcomes. *American Anthropologist* 97(3): 481-491.

- Dave, P. (1991). Community and self-financing in voluntary health programmes in India. *Health Policy and Planning* 6(1): 20-31.
- de Bayer, J. A., Preker, A.S. & Feachem, R.G.A. (2000). The role of the World Bank in International Health: Renewed Commitment and Partnership. *Social Science and Medicine* 50: 169-176.
- De Bruyn, M. (1992). Women & AIDS in Developing Countries. *Social Science & Medicine* 34(3): 249-262.
- Decosas, J. & Finlay, J. (1993). International AIDS aid: the response of development agencies to the HIV/AIDS pandemic. *AIDS* 7(supplement 1): 281-286.
- De Foneska, C. (1995). Challenges & Future Directions for Asian NGOs. pp 57-76 in Shaw.T.M. (ed) *Government- NGO Relationships in Asia. Prospects & Challenges for People-Centred Development*. Great Britain, Macmillan Press.
- DeJong, J. (2003). *Making an impact in HIV and AIDS*. London, ITDG.
- Delor, F. & Hubert, M. (2000). Revisiting the concept of 'vulnerability'. *Social Science and Medicine* 50: 1557-1570.
- Denzin, N.K. (1994). The Art and Politics of Interpretation. pp 500-515 in Denzin, N.K. & Lincoln, Y.S. (eds) *Handbook of Qualitative Research*. London, New Delhi, Thousand Oaks, Sage Publications.
- Dewan, P. K., Lal, S.S., Lonnroth, K., Wares, F., Uplekar, M., Sahu, S., Granich, R. & Chauhan, L.S. (2006). Improving tuberculosis control through public-private collaboration in India: literature review. *British Medical Journal* 332: 574-578.
- DfID. (2000). *Better Health For Poor People*. London, DfID.
- DfID. (2001). *HIV/AIDS Strategy*. London, DfID.
- DfID. (2003). *UK's Call for Action on HIV/AIDS*. London & Glasgow, DfID.
- DfID (no date) *Historical Background: Fact Sheet*. London, DfID
- Dhar, S. (2006). British 'Doctor' playing God in Kolkata. *Hindustan Times*, 12 September [on-line] <http://www.hindustantimes.com/news/1811794213,0011.htm>. [date accessed: 12/05/07]

Downing, R.G., Eglin, R.P and Bayley A.C. (1984). African Kaposi's Sarcoma and AIDS. *Lancet* 1: 478-80.

Dube, S. (2000). *Sex, Lies and AIDS*. India, Harper Collins.

Eade, D. (1997). *Capacity-Building. An Approach to People Centred Development*. UK and Ireland, Oxfam.

The Economist. (2004). Abating or Exploding? *The Economist* 371(8371): 21-23 [online] <http://web.ebscohost.com/ehost/delivery?vid=4&hid=17&sid=f421cf6c-e129-4829-aa> [date accessed 28 June 2008].

Edelman, M. (1967). *The Symbolic Uses of Politics*. Urbana, Chicago, University of Illinois Press.

Edwards, M. & Hulme, D. (1996). Too Close for Comfort? The Impact of Official Aid on Non-Governmental Organizations. *World Development* 24(6): 961-973.

Edwards, M. (1994). International Non Governmental Organizations, 'Good Government' and the 'New Policy Agenda': Lessons of Experience at the Programme Level. *Democratization* 1(3): 504-515.

Edwards, M. & Hulme, D. (1998). NGO Performance and Accountability: Introduction and Overview. Pp 3-16 in Edwards, M. & Hulme, D. (eds) *Non-Governmental Organizations Performance and Accountability. Beyond the Magic Bullet*. London, Earthscan Publications & Save The Children.

Edwards, M. & Hulme, D. (2000). Scaling up NGO impact on development: learning from experience. Pp 44-63 in Pearce, J. (ed) *Development, NGOs, and Civil Society*.

Epstein, S. (1996). *Impure Science. AIDS, Activism, and the Politics of Knowledge*. California, London, University of California Press.

Evans, C. & Lambert, H. (1997). Health-seeking strategies and sexual health among female sex workers in urban India: implications for research and service provision. *Social Science & Medicine* 44(12): 1791-1997.

Evans, C. & Lambert, H. (2008). The limits of behaviour change theory: condom use and contexts of HIV risk in the Kolkata sex industry. *Culture, Health and Sexuality*. 10(1): 27-41.

- Falcone, D. (1980). Health policy analysis: Some reflections on the state of the art. *Policy Studies Journal* 9(2): 188-197.
- Feeney, P. (1998). *Accountable Aid: Local Participation in Major Projects*. Oxford, Oxfam G.B.
- Finlay, L. (2002). "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research*. 12: 531-545.
- Finlay, L. (2003). The reflexive journey: mapping multiple routes. pp 3-20 in in Finlay, L & Gough, B. *Reflexivity a Practical Guide for Researchers in Health and Social Science*. Oxford UK, Malden USA, Carlton Australia, Blackwell Publishing.
- Finlay, L. & Gough, B. (2003). Prologue. pp IX-XI in Finlay, L & Gough, B. *Reflexivity a Practical Guide for Researchers in Health and Social Science*. Oxford UK, Malden USA, Carlton Australia, Blackwell Publishing.
- Finn, M. & Sarangi, S. (2008). Quality of Life as a mode of governance: NGO talk of HIV 'positive' health in India'. *Social Science & Medicine* 66: 1568-1578.
- Fisher, J. (1998). *Non-Governments: NGOs and the Political Development of the Third World*. Connecticut, Kumarian Press.
- Fitzgerald, R. (2001). 'Clinical Christianity': The Emergence of Medical Work as a Missionary Strategy in Colonial India, 1800-1914. pp 88-136 in Pati, B. & Harrison, M. (eds) *Health, Medicine & Empire . Perspectives on Colonial India*. Hyderabad, India, Orient Longman.
- Foucault, M. (1978). *The History of Sexuality an Introduction*. Trans R. Hurley, London, Peregrin.
- Fowler, A.(1996). Assessing NGO performance: Difficulties, dilemmas and a way ahead. Pp 143-56 In: Edwards & Hulme (eds): *Non-Governmental Organizations-performance and accountability. Beyond the magic bullet*. London, Earthscan.
- Fox, N.J. (1998). Postmodernism and Health. pp 9-22 in Peterson, A. & Waddell, C. (eds) *Health Matters. A Sociology of Illness, Prevention and Care*. Buckingham, Oxford University Press.

- French, P. (1997). *Liberty or Death. India's Journey to Independence and Division*. London, Harper Collins.
- Gangakhedkar, R.R., Bentley, M.E., Divekar, A.D., Gadkari, D., Bollinger, R.C. & Quinn, T.C. (1997). Spread of HIV infection in Married Monogamous Women in India. *Journal of the American Medical Association* 278 (23): 2090-2092.
- Garfield, S. (1994). *The End of Innocence. Britain in the Time of AIDS*. London, Boston, Faber & Faber.
- Gates, M.F. (2006). What Women Really Need. *Newsweek* 147(20): 66-67.
- Gellert, G. A. (1996). Non-Governmental Organizations in International Health: Past Successes, Future Challenges. *International Journal of Health Planning and Management* 11:19-31.
- Ghose, T., Swendeman, D., George, S. & Chowdhury, D. (2008). Mobilizing collective identity to reduce HIV risk among sex workers in Sonagachi, India: The boundaries, consciousness, negotiation framework. *Social Science & Medicine* 67: 311-320.
- Ghosh, L. (1998). Macaulay's law haunts Calcutta's gays. *Asian Age*. 5th August 1998, pl.
- Gibney, L. (1999). HIV Prevention in Developing Countries. Tenets of Behavioural and Biomedical Approaches. Pp 1-7 in Gibney, L., DiClemente, R.J. & Vermind, S.H. (eds) *Preventing HIV in Developing Countries. Biomedical and Behavioural Approaches*. New York, Boston, Dordrecht, London & Moscow, Kluwer Academic/Plenum Publishers.
- Gilada, I.S. (1991). AIDS in India. *AIDS Care* 3(4): 391-394.
- Gilks, C. F. (2001). HIV Care in non-industrialised countries. *British Medical Bulletin* 58: 171-186.
- Gilks, C., Floyd, K., Haran, D., Kemp, J., Squire, B. & Wilkinson, D. (2002). *Sexual Health and Health Care: Care and Support for People With HIV/AIDS in Resource-Poor Settings*. Liverpool, DFID.

- Gilmore, N. & Somerville, M.A. (1994). Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming 'Them' and 'Us'. *Social Science and Medicine* 39 (9): 1339-1358.
- Gilson, L., Sen, P.D., Mohammed, S. & Mujinja, P. (1994). The potential of health sector non-governmental organizations: policy options. *Health Policy and Planning* 9(1): 14-24.
- Godbole, S. & Mehendale, S. (2005). HIV/AIDS Epidemic in India: Risk Factors, Risk Behaviours and Strategies for Prevention and Control. *Indian Journal of Medical Research* 121: 356-368.
- Godlee, F. (1994). WHO in crisis. *British Medical Journal* 309:1424-8.
- Godlee, F. (1994). WHO in retreat: is it loosing its influence? *British Medical Journal* 309:1491-5.
- Goldacre, B. (2009). HIV and AIDS: debate or denial? *The Guardian*, 24th October, p14.
- Goldin, C. S. (1994). Stigmatization and AIDS: Critical Issues in Public Health. *Social Science and Medicine* 39(9):1359-1366.
- Gonzales, V., Grosskurth, H., Guinness, L., Pangare, V. & Sethi, G. (1999). *Evaluation of Four Partner Projects of the West Bengal Sexual Health Project*. London, Family Health International. Unpublished.
- Gordon, C. (ed) (1980). *Michel Foucault. Power/Knowledge. Selected Interviews and Other Writings 1972-1977*. New York, London, Prentice Hall.
- Government of India. (2000). *India Responds to HIV/AIDS: A Strategic Response to the HIV Epidemic by the Government of India, the UN and its Development Partners in India*. Unpublished report, New Delhi.
- Government of West Bengal, Department of Health & Family Welfare (2000) *Health & Family Welfare in West Bengal*. Unpublished report, Kolkata.
- Green, A. (1992a). *An Introduction to Health Planning in Developing Countries*. Oxford, New York, Tokyo, Oxford University Press.

- Green, A. (1992b). The role of non-governmental organizations and the private sector in the provision of health care in developing countries. *International Journal of Health Planning and Management* 2:37-58.
- Green, A. & Matthias, A. (1997). *Non-Governmental Organizations and Health in Developing Countries*. Basingstoke, London, Macmillan Press.
- Gupta, I. & Panda, S. (2002). The HIV/AIDS Epidemic in India: Looking Ahead. pp 179-196 in Panda, S., Chatterjee, A. & Abdul-Quader, S.A.(eds) *Living With The AIDS Virus: The epidemic and the Response in India*. New Delhi, Thousand Oaks, London, Sage Publications.
- Gupta, K.R. & Pillay, D. (2007). HIV resistance and the developing world. *International Journal of Antimicrobial Agents* 29: 510-517.
- Gwyn, R. (1999). 'Killer bugs', 'silly buggers' and 'politically correct pals': competing discourses in health scare reporting. *Health* 3(3): 335-345.
- Hall, S. (2001). Foucault: Power, Knowledge and Discourse. pp 72-81 in Wetherell, M., Taylor, S. & Yates, S. (eds) *Discourse Theory and Practice: A Reader*. London, Thousand Oaks, New Delhi, Sage Publications.
- Halmshaw, C. & Hawkins, K. (2004). Capitalising on Global HIV/AIDS Funding: The Challenge for Civil Society and Government. *Reproductive Health Matters* 12(24): 35-41.
- Ham, C. (1991). Analysis of health policy- principles and practice. *Scandinavian Journal of Social Medicine* 46(supplement): 62-66.
- Harper, D. (2003). Developing a critically reflexive position using discourse analysis. pp78-92 in Finlay, L & Gough, B. *Reflexivity a Practical Guide for Researchers in Health and Social Science*. Oxford UK, Malden USA, Carlton Australia, Blackwell Publishing.
- Harrison, M. (2001). Medicine and Orientalism: Perspectives on Europe's encounter with Indian Medical Systems. Pp 37-87 in Pati, B. & Harrison, M. (eds) *Health, Medicine & Empire. Perspectives on Colonial India*. Hyderabad, India, Orient Longman.

- Harrison, M. (1994). *Public Health in British India. Anglo-Indian Preventative Medicine 1859-1914*. Greta Britain, Cambridge University Press.
- Hawkins, K. (2000). *Enabling environments: building effective community led responses to HIV/AIDS*. Unpublished report for DFID.
- Hearst, N. & Chen, S. (2004). Condom promotion for AIDS prevention in the developing world: is it working? *Studies in Family Planning*. 35(1): 39-47.
- Heehs, P. (1988). *India's Freedom Struggle. A Short History 1857-1947*. Oxford, Oxford University Press.
- Helmich, H. (1999). Introduction. Pp 3-6 in Smillie, I. & Helmich, H. (eds) *Stakeholders: Government-NGO Partnerships for International Development*. London, Earthscan.
- Heywood, M. (2004). Drug access, patents and global health: 'chaffed and waxed sufficient'. Pp 27-41 in Poku, N.K. & Whiteside, A. (eds) *Global Health and Governance: HIV/AIDS*. Basingstoke, New York: Palgrave Macmillan.
- Hilhorst, D. (2003). *The Real World of NGO: Discourses, Diversity and Developments*. London, New York, Zed Books.
- Holden, S. (2003). *AIDS on the Agenda*. London, Oxford, Action AID, Oxfam GB & Save The Children.
- Hogwood, B.W. & Gunn, L.A. (1984). *Policy Analysis for the Real World*. Oxford, New York, Oxford University Press.
- Human Rights Watch. (2002). *Epidemic of Abuse*. [On line] Available: http://www.hrw.org/reports/2002/india2/india0602_01.htm [date accessed: 10/07/02].
- Hutnyk, J. (1996). *The Rumour of Calcutta. Tourism, Charity and the Poverty of Representation*. London, New Jersey, Zee.
- Jain, M.K., John, T.J. & Keusch, G.T. (1994). Epidemiology of HIV and AIDS in India. *AIDS*, 8 (supplement 2): 61-75.
- Jalal, A. (1995). *Democracy and Authoritarianism in South Asia*. Cambridge, Cambridge University Press.

- James, L. (1997). *Raj, The Making and Unmaking of British India*. Great Britain, Little, Brown and Company.
- Jana, S. (2004). The Sonagachi Project: A sustainable community intervention programme. *AIDS Education & Prevention* 16(5): 405-414.
- Jana, S. & Singh, S. (1995). Beyond Medical Model of STD Intervention- Lessons from Sonagachi. *Indian Journal of Public Health* XXXIX (3):125-131.
- Jana, S., Bandyopadhyay, N., Mukherjee, S., Dutta, N., Basu, I. & Saha, A. (1998). STD/HIV Intervention With Sex Workers in West Bengal, India. *AIDS* 12, (supplement B): 101-108.
- Jana, S. & Banerjee, B. (1999) *Learning to Change. Seven Years' Stint at Sonagachi 1992-1999*. Unpublished report, Calcutta.
- Jayaraman, K. S. (1985). India against AIDS. *Nature* 318 (6066):103.
- Joffe, H. (1995). Social representations of AIDS: Towards encompassing issues of power. *Papers on Social Representation* 4(1) 29-40.
- Joffe, H. (1996). AIDS research and prevention: A social representational approach. *British Journal of Medical Psychology* 69:169-190.
- John, M.E. & Nair, J. (1998) A Question of Silence? An Introduction. pp 1-51 in John, M.E. & Nair, J. (eds) *A Question of Silence. The Sexual economies of Modern India*.
- Judd, D. (2004). *The Lion and the Tiger. The Rise and Fall of the British Raj 1600-1947*. Oxford, New York, Oxford University Press.
- Kallings, L.O. (2008). The first postmodern pandemic: 25 years of HIV/AIDS. *Journal of Internal Medicine*, 263: 218-243.
- Karnik, N. S. (2001). Locating HIV/AIDS and India: Cautionary Notes on the Globalization of Categories. *Science, Technology & Human Values* 26 (3): 322-348.
- Kickbusch, I. & de Leeuw, E. (1999). Global Public Health: Revisiting Public Policy at the Global Level. *Health Promotion International* 14(4): 285-288. [on-line] Available: <http://heapro.oxfordjournals.org/cgi/content/full/14/4/285>. [date accessed 14/07/2007].
- Kickbusch, I. (2000). The development of international health policies- accountability intact? *Social Science and Medicine* 51: 979-989.

- Kilby, P. (2006). Accountability for Empowerment: Dilemmas Facing Non-Governmental Organizations. *World Development* 34(6): 951-963.
- Kitahata, M.M., Tegger, M.K., Wagner, E.H. & Holmes, K.K. (2002). Comprehensive health care for people infected with HIV in developing countries. *British Medical Journal* 325: 954- 957.
- Korten, D. C. (1987). Third Generation NGO Strategies: A key to People-centred Development. *World Development* 15 (Supplement): 145-159.
- Kumar, R. (1993). *The History of Doing. An illustrated history of movements for women's rights and feminism in India 1800-1990*. London, New York, Verso.
- Kumarasamy, N., Vallabhaneni, S., Flanigan, T.P., Mayer, K.H. & Solomon, Suniti. (2005). Clinical profile of HIV in India. *Indian Journal of Medical Research* 121: 377-394.
- La Fond, A. (1995). *Sustaining Primary Health Care*. London, Save the Children & Earth Scan Publications.
- Laino, C. (1995). HIV rates may become highest in the World. Medical Tribune News Service.
- Lamprey, P. R. (2002). Reducing heterosexual transmission of HIV in poor countries. *British Medical Journal* 324: 207-11.
- Lee, K., Buse, K. & Fustukian, S. (2002). An Introduction to Global Health Policy, 3-17 in Lee, K., Buse, K. & Fustukian, S. (eds) *Health Policy in a Globalising World*. Cambridge, Cambridge University Press.
- Lee, K. & Mills, A. (1982). *Policy-Making and Planning in the Health Sector*. London, Canberra, Croom Helm.
- Lewis, M. & Bamber, S. (1997). Introduction. pp 1-17 in Lewis, M. & Bamber, S. (eds) *Sex, Disease & Society: A Comparative History of Sexually Transmitted Diseases and HIV/AIDS in Asia and the Pacific*. Westport Connecticut & London, Greenwood Press.
- Lieten, G. K. (1999). Panchayat Leaders in a West Bengal District. pp 265-282 in Jha, S. N. & Mather, P. C. (eds) *Decentralization and Local Politics*. New Delhi, Thousand Oaks, London, Sage Publications.

- Lichfield, J. (1997). Lethal epidemic is much larger than feared. *The Independent*, 27th November, 1997, p7.
- Long, L.D. (1996). Introduction: Counting Women's experiences. pp 1-20 in Long, L.D. & Ankrah, M. (eds) *Women's Experiences with HIV/AIDS*. New York: Columbia University Press.
- Loomba, A. (1998). *Colonialism/Postcolonialism*. London & New York, Routledge.
- Lorgen, C.C. (1998). Dancing with the State: The role of NGOs in Health Care and Health Policy. *Journal of International Development* 10: 323-339.
- Lupton, D. (1993). Risk as moral danger: The social and political functions of risk discourse in public health. *International Journal of Health Services* 23(3): 425-435.
- Lush, L., Walt, G. & Ogden, J. (2003). Transferring policies for treating sexually transmitted infections: what's wrong with global guidelines? *Health Policy and Planning*. 18(1): 18-30.
- Madhusree, M. (2006). The Prostitutes Union. *Scientific American* 294(4): 36-37.
- Mageli, E. (2005). Exploring the NGO Environment in Kolkata: The Universe of Unnayan, Chhinnamul and Sramajaibi. *The European Journal of Development Research* 17(2): 249-269.
- Mahal, A. & Rao, B. (2003). HIV/AIDS epidemic in India: An economic perspective. *Indian Journal of Medical Research* 121: 582-600.
- Mane, P. & Aggleton, P. (2001). Gender & HIV: What do men have to do with it? *Current Sociology* 49(6): 23-37.
- Mann, J. (1991). Where are we now? AIDS. *Health Policy & Planning* 6(2): 191-193.
- Mann, J.M. & Tarantola, D.J.M. (eds) (1996). *AIDS in the World II. Global Dimensions, Social Roots, and Responses*. New York, Oxford: Oxford University Press.
- Mann, J. M. & Kay, K. (1991). Confronting the Pandemic: The World Health Organization's Global Programme on AIDS, 1986-1989. *AIDS* 5(supplement 2): 221-229.
- Marshall, C. & Rossman, G. B. (1995). *Designing Qualitative Research*. Thousand oaks, London & New Delhi, Sage Publications.

- McCoy, M. & McCully, P. (1993). *The Road from Rio: An NGO Action Guide to Environment and Development*. The Netherlands, International Books.
- McGregor, A. (1997). World Bank reports on priorities for HIV and AIDS. *The Lancet* 350(9089): 1456.
- Mercer, M.A., Liskin, L. & Scott, S.J. (1991). The role of non-governmental organizations in the global response to AIDS. *AIDS Care* 3(3): 265-270.
- Merson, M.H., O'Malley, J., Serwadda, D. & Apisuk, C. (2008). The history and challenge of HIV prevention. *The Lancet*. 372: 475-488.
- Mohan, R. & Mohan, R. (1998). Impact of NGO Intervention in the Knowledge and Practices of Tribal Women of West Bengal. *South Asian Anthropologist* 19(2): 87-93.
- Mooney, A. & Sarangi, S. (2005). An ecological framing of HIV prevention intervention: a case study of non-government organizational work in the developing world. *Health* 9(3): 275-296.
- Moore, M. & Stewart, S. (2000). Corporate governance for NGOs? Pp80-90. In: Eade, D. (Editor). *Development NGOs and Civil Society*. Oxford, Oxfam.
- Mosse, D. (1994). Authority, Gender and Knowledge: Theoretical Reflections on the Practice of Participatory Rural Appraisal. *Development and Change* 25: 497-526.
- Mudur, G.S. (2000). The estimate of HIV cases in India has turned into a guessing game riddled with controversy. *The Calcutta Telegraph*. 30th July 2000, p2.
- Muthuswamy, V. (2005). Ethical Issues in HIV/AIDS Research. *Indian Journal of Medical Research* 121: 601-610.
- NACO, Ministry of Health & Family Welfare, Government of India (1999) *Country Scenario 1998-99*. New Delhi: NACO.
- NACO, Ministry of Health & Family Welfare, Government of India (2000), *Combating HIV/AIDS in India 1999-2000*. New Delhi: NACO.
- NACO, Ministry of Health & Family Welfare, Government of India. (2008). *UNGASS Country Progress Report 2008 India*. New Delhi.
- NACO. (No date). *India Responds to HIV/AIDS*. India.

- Nag, M. (2002). Empowering female sex workers for AIDS prevention and far beyond: Sonagachi shows the way. *Indian Journal of Social Work* 63(4): 473-501.
- Nau, E. (1994). Time for realism over HIV infection. *The Lancet* 344(8921): 535-535.
- Nguyet Emi, J. (1997). Of desire, the Farang, and textual excursions: Assembling 'Asian AIDS'. *Cultural Studies* 11(1), 64-77.
- Nsutebu, E. F., Walley, J.D., Mataka, E. & Simon, C.F. (2001). Scaling up HIV/AIDS and T.B. home-based care: Lessons from Zambia. *Health Policy & Planning* 16(3): 240-247.
- Ogden, J.A. & Porter, J.D.H. (2000). The Politics of Partnership in Public Health: Researching Tuberculosis Control in India. *Social Policy & Administration*. 34(4): 377-391.
- Ogden, J., Walt, G. & Lush, L. (2003). The politics of 'branding' in policy transfer: the case of DOTS for tuberculosis control. *Social Science & Medicine*. 57: 179-188.
- O'Keefe, E. (1995). The World Bank: health policy, poverty and equity. *Critical Public Health* 6(3): 28-35.
- O'Malley, J., Nguyen, V.K. & Lee, S. (1996). Nongovernmental Organizations. Pp 341-361 in Mann, J. & Tarantola, D. (eds) *AIDS in the World II. Global Dimensions, Social Roots, and Responsibilities*. New York, Oxford, Oxford University Press.
- Ojha, S.K. (ed). (1999). *Key Information on Prevention and Control of HIV/AIDS/STD West Bengal*. West Bengal AIDS Prevention and Control Society, Kolkata, India. Unpublished.
- Oliver, B. (1966). *The British Red Cross in Action*. London, Faber & Faber.
- Oppenheim, M. K. (1994). HIV transmission and the balance of power between men and women. a global view. (1994). *Health Transition Review*. Volume 4 (Supplement): 217-240.
- Overseas Development Administration. (1995). *Targeted Interventions to Promote Sexual Health in Selected Urban and Rural Areas of India*. Project Memorandum, London, Overseas Development Administration.

- Padian, N., Buve, A., Balkus, J., Serwadda, D. & Cates, W. (2008). Biomedical interventions to prevent HIV infection: evidence, challenges, and way forward. *The Lancet*. 372: 585-599.
- Padma, T.V. (2008). India continues crackdown, dismissing hundreds of AIDS groups. *Nature Medicine* 14(3): 227.
- Pais, P. (1996). HIV and India: Looking into the Abyss. *Tropical Medicine and International Health* 1(3):295-304.
- Paiva, V., Ayres, J.R., Buchalla, C.M. & Hearst, N. (2002). Building partnerships to respond to HIV/AIDS: non-governmental organizations and universities. *AIDS* 16(supplement 3): 76-82.
- Palmer, N., Strong, I. & Sondorp, E. (2006). Contracting out health services in fragile states. *British Medical Journal* 332: 718-721. [on-line] Available: <http://www.bmj.com/cgi/content/full/332/7543/718> [date accessed 14/07/2007].
- Panda, S. (2000). *Rapid Situational Assessment: Opioid/Opiate Drug Use in Calcutta*. Conducted by RIICE, Society for Applied Studies, Calcutta on behalf of UNESCO Five City RSA, Kolkata, India. Unpublished.
- Panda, S. (2002). The HIV/AIDS Epidemic in India: An Overview. pp 17-35 in Panda, S., Chatterjee, A. & Abdul-Quader, A.S. (eds) *Living With The AIDS Virus: The Epidemic and the Response in India*. New Delhi, Thousand Oaks, London. Sage Publications.
- Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine* 57: 13-24.
- Parker, R. (2006). Editorial. *Global Public Health* 1(1):1-3.
- Parkhurst, J.O. & Lush, L. (2004). The political environment of HIV: lessons from a comparison of Uganda and South Africa. *Social Science & Medicine*. 59: 1913-1924.
- Patnak, E. (1998a). No place for AIDS patients in city hospitals. *Asian Age*. 1st December 1998.

- Patton, C. (1990). What Science Knows: Formations of AIDS Knowledge. pp 1- 17 in Aggleton, P., Davies, P. & Hall, G. (eds). *AIDS, Individual, Cultural and Policy Dimensions*. London, New York, Philadelphia, Falmer Press.
- Patton, C. (1992). From Nation to Family: Containing "African AIDS". pp 218-234 in Parker, A., Russo, M., Sommer, D. & Yaeger, P. (eds) *Nationalisms and Sexualities*. London, New York, Routledge.
- Patton, C. (1993). 'With Champagne and Roses'. Women at Risk from/in AIDS Discourse. pp 165-187 in Squire, C. (ed) *Women and AIDS. Psychological Perspectives*. London, Sage Publications.
- Paul, N. (2007). Discrimination against people living with HIV/AIDS in India: Educated persons as perpetrators. *Journal of Infection* 54: 103-104.
- Payne, G. & Payne, J. (2004). *Key Concepts in Social Research*. London, Thousand Oaks, New Delhi, Sage Publications.
- Pearce, J. (2000). Development, NGOs, and civil society: the debate and its future. pp 15-43 In: Eade, D. (Editor): *Development, NGOs and Civil Society*. G.B. Oxfam.
- Persson, A., Race, K. & Wakeford, E. (2003). HIV health in context: negotiating medical technology and lived experience. *Health: an interdisciplinary journal for the social study of health, illness and medicine*. 7(4): 397-415.
- Peterson, A. & Waddell, C (1998). Introduction. pp 3-8 in Peterson, A. & Waddell, C. (eds) *Health Matters. A Sociology of Illness, Prevention and Care*. Buckingham, Oxford University Press.
- Peters, D.H., Yazbeck, A.S., Sharma, R.R., Ramana, G.N.V., Pritchett, L.H. & Wagstaff, A. (2002). *Better Health Systems for India's Poor. Findings, Analysis, and Options*. Washington, D.C, The World Bank.
- Piot, P. (1996). Why UNAIDS? pp 370-371 in Mann, J. & Tarantola, D. (eds) *AIDS in the World II*. New York, Oxford, Oxford University Press.
- Piot, P. (1998). The science of AIDS: A tale of two worlds. *Science*. 280(19 June): 1844-1845.
- Piot, P. (2001). Introduction. *British Medical Bulletin* 58: 3-5.

- Piot, P., Plummer, F.A., Mhalu, F.S., Lamboray, Jean-Louis., Chin, J. & Mann, M. (1988). AIDS: An International Perspective. *Science* 239 (5 February): 573-579.
- Piot, P. & Aggleton, P. (1998). The Global Epidemic. *AIDS Care* 10(supplement 2): 201-208.
- Poddar, A.K., Poddar, D.S. & Mandal, R.N. (1996). Perception about AIDS among Residents of a Calcutta Slum. *Indian Journal of Public Health*, XXXX (1): 4-9.
- Poku, N.K. (2002). The Global AIDS Fund: context and opportunity. *Third World Quarterly* 23(2): 283-298.
- Poku, N. K. & Whiteside, A. (2002). Global Health and the politics of governance: an introduction. *Third World Quarterly* 23(2):191-195.
- Poku, N. K. & Whiteside, A. (eds). (2004). *Global Health & Governance. HIV/AIDS*. Basingstoke, New York, Palgrave Macmillan.
- Poore, P. (2004). The Global Fund to fight Aids, Tuberculosis and Malaria (GFATM). *Health Policy and Planning* 19(1): 52-53.
- Porter, J.D.H., Ogden, J.A., Ranganadha Rao, P.V., Rajedesh, D., Buskade, R.A. & Soutar, D. (2002). Lessons in integration- operations research in an Indian leprosy NGO. *Leprosy Review* 73: 147-159.
- Porter, J. D.H., Ogden, J.A., Ranganadha Rao, P.V., Prabhakar Rao, V., Rajesh, D., Buskade, R.A. & Soutar, D. (2004). Introducing operations research into management and policy practices of a non-governmental organization (NGO): a partnership between an Indian leprosy NGO and an international academic institution. *Health Policy & Planning* 19(2): 80-87.
- Porter, J.D.H., Ogden, J.A., Ranganadha Rao, P.V., Prabhakar,Rao, V., Rajesh, D., Buskade, R.A. & Soutar, D. (2002). Lessons in integration-operations research in an Indian leprosy NGO. *Leprosy Review* 73: 147-159.
- Porter, S.B. (1993). Public knowledge and attitudes about AIDS among adults in Calcutta, India. *AIDS Care* 5(2): 169-176.
- Pradeep, K. (2002). Interventions among Men Who Have Sex With Men. pp 112-129 in Panda, S., Chatterjee, A. & Abdul-Quader, S.A.(eds) *Living With The AIDS Virus: The*

epidemic and the Response in India New Delhi, Thousand Oaks, London, Sage Publications.

Priya, R. (1994a). AIDS, Public Health and the Panic Reaction (Part 1). *The National Medical Journal of India* 7(5): 235-240.

Priya, R. (1994b). AIDS, Public Health and the Panic reaction (Part 2). *The National Medical Journal of India*. 7(6): 288-291.

Priya, R. (2001). Disability Adjusted Life years as a Tool for Public Health Policy: a critical Assessment. pp 154-173 in Qadeer, I., Sen, K. & Nayar, K.R. (eds) *Public Health and the Poverty of reforms. The South Asian Predicament*. New Delhi, Thousand Oaks, London, Sage publications.

Priya, R. & Sathyamala, C. (2007). Contextualising AIDS and human development: Long-term illness and death among adults in labouring low-caste groups in India. *AIDS Care* 19(supplement 1): S35-S43.

Puri, J. (1999). *Woman, Body, Desire in Post-Colonial India. Narratives of Gender and Sexuality*. London, New York, Routledge.

Radhakrishnan, R. (1992). Nationalism, Gender, and the Narrative of Identity. pp77-95 in Parker, A., Russo, M., Sommer, D. & Yaeger, P. (eds) *Nationalisms and Sexualities*. London, New York, Routledge.

Raghavulu, C.V. & Narayana, E.A. (1999). Reforms in Panchayati Raj: A Comparative Analysis of Andhra Pradesh, Karnataka and West Bengal. pp 117-130 in Jha, S N & Mather, P C (eds) *Decentralisation and Local Politics*. London, New Delhi, Thousand Oaks, Sage Publications.

Rajkova, S. (2002). HIV and Law in India. Pp 166- 178 in Panda, S., Chatterjee, A. & Abdul-Quader, S.A.(eds) *Living With The AIDS Virus: The Epidemic and the Response in India*. New Delhi, Sage Publications.

Ram, E. P. & Singh, A. C. (1991). Role of Women in Prevention and Control of AIDS. *Nursing Journal of India* LXXXII(4): 119-120.

Ramakrishnan, A. & Alexander, A. (2006). Practicing Theory: Management in HIV Intervention. *Harvard International Review* Summer: 58-61.

- Ramasundaram, S. (2002). Can India Avoid Being Devastated by HIV? *British Medical Journal* 324: 182-183.
- Rao, K.S. (1999). Sexual lifestyle of long distance lorry drivers in India: questionnaire survey. *British Medical Journal* 318: 162-163.
- Rao, S. (1999). Woman-as-symbol: the intersections of identity politics, gender, and Indian nationalism. *Women's Studies International Forum*. 22(3): 317-328.
- Rao Gupta, G., Parkhurst, J. O., Ogden, J., Aggleton, P. & Mahal, A. (2008). Structural approaches to HIV prevention. *The Lancet*. 372: 764-775.
- Reghunath, R. (1997). Home Care of Persons with AIDS. *The Nursing Journal of India* LXXXVIII(7): 153-157.
- Richardson, L. (1994). Writing. A method of Inquiry. pp516-529 in Denzin, N.K. & Lincoln, Y.S. (eds) *Handbook of Qualitative Research*. London, New Delhi, Thousand Oaks, Sage Publications.
- Rosenbrock, R., Dubois-Arber, F., Moers, M., Pinell, P., Schaeffer, D. & Setbon, M. (2000). The normalization of AIDS in Western European countries *Social Science & Medicine* 50: 1607-1629.
- Rowden, R. (2004). *Blocking Progress. How the fight against HIV/AIDS is being undermined by the World Bank and the International Monetary Fund*. Unpublished report for Action Aid International USA, Global AIDS Alliance, Student Global Aids Campaign, Results Education Fund.
- Roy Chowdhury, N. N. (1992). Problem of AIDS in India especially in women. *Early Human Development* 29: 225-229.
- Said, E. (1978). *Orientalism: Western Concepts of the Orient*. Harmondsworth, Penguin.
- Salamon, L.M. (1994). The Rise of the Nonprofit Sector. *Foreign Affairs* 73(4): 109-122.[on-line]Available:
<http://web.ebscohost.com/ehost/delivery?vid=7&hid=8&sid=bcfe40a7-ad2d-4fb6-8c0...> [date accessed 31/08/2008].
- Sarantakos, S. (1998). *Social Research*. 2e Basingstoke, Macmillan.

- Sarkar, S. (2008). Nationalism and poverty: discourses of development and culture in 20th century India. *Third World Quarterly*. 29(3): 429-445.
- Scholte, J.A. (1997). Global capitalism and the state. *International Affairs* 73(3): 427-452.
- Schoub, B.D. (1999). *AIDS and HIV in perspective*. 2e. Cambridge, Cambridge University Press.
- Seal, A. (2000). *Negotiating Intimacies: Sexualities, Birth Control and Poor Households*. Calcutta, Stree.
- Seckinelgin, H. (2008). *International Politics of HIV/AIDS. Global Disease- Local Pain*. London, Routledge.
- Seidel, G. & Vidal, L. (1997). The implications of 'medical', 'gender in development' and 'culturalist' discourses for HIV/AIDS policy in Africa. pp 59-87 in Shore, C. & Wright, S. (eds) *Anthropology of Policy. Critical Perspectives on Governance and Power*. London, Routledge.
- Sen, S. (1999). Some aspects of State-NGO Relationships in India in the Post-Independence Era. *Development & Change* 30: 327-355.
- Sethi, Geeta. (2002). AIDS in India: The Government's Response. pp 37-61 in Panda, S., Chatterjee, A. & Abdul-Quader, A.S. (eds) *Living With The AIDS Virus: The Epidemic and the Response in India*. New Delhi, Thousand Oaks, London. Sage Publications.
- Shadlen, K.C. (2007). The Political Economy of AIDS Treatment: Intellectual Property and the Transformation of Generic Supply. *International Studies Quarterly* 51: 559-581.
- Sheikh, K., Porter, J., Kielmann, K. & Rangan, Sheela. (2006). Public-private partnerships for equity of access to care for tuberculosis and HIV/AIDS: lessons from Pune, India'. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100: 312-320.
- Shenton, J. (1998). *Positively False. Exposing the Myths around HIV and AIDS*. London, New York, Taurus.
- Shilts, R. (1988). *And The Band Played On*. Harmondsworth, Penguin.

- Shirin, S. (1995). Mixed Blessings. *Harvard International Review* 18(1): 54-58.
- Shore, C. & Wright, S. (1997). Policy: a new field of anthropology. Pp 3-39 in Shore, C. & Wright, S. (eds) *Anthropology of policy: critical perspectives on governance and power*. London, New York, Routledge.
- Singh, Y.N. & Malaviya, A.N. (1994). Long Distance Truck Drivers in India: HIV infection and their possible role in disseminating HIV into rural areas. *International Journal of STD and AIDS* 5: 137-138.
- Singhal, A. & Rogers, E.M. (2003). *Combating AIDS. Communication Strategies in Action*. New Delhi, Thousand Oaks, London, Sage Publications.
- Sircar, D. D. & Tewari, H.R. (1996). Migration, Mobility and HIV Infection. *Social Action* 46 (4): 467-480.
- Sivaram, S. & Celentano, D. D. (2003). Training outreach workers for AIDS prevention in rural India: is it sustainable? *Health Policy and Planning* 18(4), 411-420.
- Sleightholme, C. & Sinha, I. (1996). *Guilty without Trial. Women in the Sex Trade in Calcutta*. Calcutta: Stree.
- Smillie, I. (1999). At Sea in a Sieve? Trends and Issues in the Relationship Between Northern NGOs and Northern Governments. Pp 7-35 in Smillie, I. & Helmich, H. (eds) *Stakeholders: Government-NGO Partnerships for International Development*. London, Earthscan.
- Sontag, S. (1991). *Illness as Metaphor. AIDS and its Metaphors*. Harmondsworth, Penguin Books.
- The Statesman, (2001). Sex worker's mela irks NGOs. *The Statesman*, 4 March 2001, p12.
- St John, R., Clifford, M. Zacarias, F. & Mann, J. (1988). The Global Programme on AIDS. *AIDS and Public Policy Journal* 3(4): 14-19.
- Stefanini, A. (1995). Sustainability: the role of NGOs. *World Health Forum* 16: 42-46.
- Stiglitz, J. (2002). *Globalization and its Discontents*. Hammondsworth, Penguin.

Taylor, S. (2001a). Locating and Conducting Discourse Analytic Research. pp 7-48 in Wetherell, M., Taylor, S. & Yates, S. J. (Eds) *Discourse as Data. A Guide for Analysis*. London, Thousand Oaks, New Delhi, Sage Publications.

Taylor, S. (2001b). Evaluating and Applying Discourse Analytic Research. pp311-330 in Wetherell, M., Taylor, S. & Yates, S. J. (Eds) *Discourse as Data. A Guide for Analysis*. London, Thousand Oaks, New Delhi, Sage Publications.

Thomas, F. (2008). Indigenous narratives of HIV/AIDS: morality and blame in a time of change. *Medical Anthropology*. 27(3): 227-256.

Timberlake, S. (1998). UNAIDS: Human Rights, Ethics and Law. *Health and Human Rights* 3(1): 87-106.

UNAIDS. (1998). *Guide to the strategic planning process for a national response to AIDS*. Geneva. UNAIDS

UNAIDS. (2000). *Report on the Global HIV/AIDS epidemic*. Geneva. UNAIDS

UNAIDS. (2004). *Report on the Global AIDS Epidemic*. 4th Global Report, June 2004. Geneva. UNAIDS

UNAIDS (2005) *Intensifying HIV Prevention*. Policy Position Paper. Geneva. UNAIDS

UNAIDS. (2006). *Essential programmatic Actions for HIV Prevention*. Geneva, UNAIDS

UNAIDS 2007. *India expands monitoring of AIDS epidemic*. Press release, 12th June 2007. Geneva, UNAIDS

UNAIDS. (2008). *Substantial increases in HIV prevention efforts producing results, but not enough to turn back the epidemic*. Press release, 29th July 2008. Geneva, UNAIDS

UNAIDS (No date). *A Joint Response to AIDS*. Geneva, UNAIDS

UNAIDS & WHO. (2007). *India expands monitoring of AIDS epidemic*. Press Statement 12th June 2007, Geneva, UNAIDS

UNAIDS & WHO. (2008). *Asia: AIDS epidemic update. Regional Summary*. Switzerland.

United Nations (1996). *HIV/AIDS and Human Rights. International Guidelines*. New York, Geneva,

United Nations General Assembly (2001) *Final Declaration of Commitment on HIV/AIDS*. (27.06.2001). [on-line] Available: <http://www.hivnet.ch:8000/asia/sea-aids/viewR?2794> [date accessed:12/12/01].

Uphoff, N. (1998). Why NGOs are not a Third Sector: A Sectoral Analysis with Some Thoughts on Accountability, Sustainability and Evaluation. Pp17-30 in Edwards, M. & Hulme, D. (Eds) *Non-Governmental Organizations. Performance and Accountability: Beyond the Magic Bullet*. London, Save The Children & Earth Scan Publications.

Van Diesen, A. (1998). *The Quality of British Aid to India- a Christian Aid Report*. [on-line] Available: <http://www.christian-aid.org.uk/indepth/9807baid/britaid1.htm>. [accessed on: 31.01.01].

Verma, R. K. & Roy, T.K. (2002). HIV Risk Behaviour and the Sociocultural Environment in India. Pp 77-90 in Panda, S., Chatterjee, A. & Abdul-Quader, A.S. (eds) *Living With The AIDS Virus: The Epidemic and the Response in India*. New Delhi, Sage Publications.

Waldby, C. (1996). *AIDS and the Body Politic: Biomedicine and Sexual Difference*. London, New York, Routledge.

Walliman, N. (2006). *Social Research Methods*. London, Thousand Oaks, New Delhi, Sage Publications.

Walt, G. & Gilson, L. (1994). Reforming The Health Sector in Developing Countries: The Central Role of Policy Analysis. *Health Policy And Planning* 9(4): 353-70.

Walt, G. (1993). WHO under stress: Implications for health policy. *Health Policy* 24:125-144.

Walt, G. (1994). *Health Policy: An Introduction to Process & Power*. London, New Jersey, Zed Books.

Walt, G., Lush, L. & Ogden, J. (2004). International Organizations in Transfer of Infectious Diseases: Iterative Loops of Adoption, Adaptation, and Marketing. *Governance: An International Journal of Policy, Administration and Institutions*. 17(2); 189-210.

- Watney, S. (1996). "Risk Groups" or "risk behaviours"? pp 431-432 in Mann, J.M. & Tarantola, D.J.M. (eds) *AIDS in the World II. Global Dimensions, Social Roots, and Responses*. New York, Oxford: Oxford University Press.
- Watney S. (1988). AIDS, "moral panic theory" and "homophobia". In Aggleton, P. & Homans, H. (eds) *Social Aspects of AIDS*. Lewes, Falmer Press.
- Webster, N. (1992). *Panchayati Raj and The Decentralisation of Development Planning in West Bengal*. Calcutta, New Delhi, K. P. Bagchi & Company.
- Weeks, J. (1989). AIDS. The Intellectual Agenda. pp 1-19 in Aggleton, P, Hart, G. & Davis, P. (eds) *AIDS- Social Representations and Social Practices*. Lewes and Philadelphia, The Falmer Press.
- West Bengal Sexual Health Project (1997). *Behaviour Change Communication in Sexual Health Interventions*. Technical Series: 3. Kolkata, West Bengal Sexual Health Project.
- West Bengal Sexual Health Project. (1998). *Report of Point Prevalence Survey, 1998 at Sonagachi, Calcutta*. Kolkata. Unpublished.
- West Bengal Sexual Health Project. (1999a). *Needs assessment in Sexual Health Interventions*. Kolkata. Unpublished
- West Bengal Sexual Health Project. (1999b). *Training Manual on Sex and Sexuality*. Kolkata. Unpublished.
- West Bengal Sexual Health Project. (1999c). *Report on Baseline wave 1999: HIV Risk Behaviour Sentinel Surveillance Survey in West Bengal*. Kolkata, Unpublished.
- West Bengal Sexual Health Project. (1999d). *Training Manual on Basics of HIV/AIDS*. Kolkata, Unpublished.
- West Bengal Sexual Health Project (no date) *Programme Planning for Sexual Health Interventions*. Technical Series I(Draft) Kolkata, Unpublished.
- West Bengal State AIDS Prevention & Control Society (1999) *AIDS: A Dreadful but Preventable Disease*. Department of Health & Family Welfare, Government of West Bengal, Kolkata.

Wetherell, M., Taylor, S. & Yates, S. (2001). Introduction. Pp 1-8 in Wetherell, M., Taylor, S. & Yates, S. (eds) *Discourse Theory and Practice: A Reader*. London, Thousand Oaks, New Delhi, Sage Publications.

Wilton, T. (1997). *En-Gendering AIDS. Deconstructing Sex, Text and Epidemic*. London, Thousand Oaks, New Delhi, Sage Publications.

Wolffers, I. (1997). Culture, media and HIV/AIDS in India. *The Lancet* 349: 52-54.

Wolffers, I. (2000). Biomedical and development paradigms in AIDS prevention. *Bulletin of the World Health Organization* 78 (2): 267-271.

World Bank. (1993). *World Development Report 2003: Investing in Health*. World Bank, Washington DC.

World Bank. (1996). *The World Bank's Partnership with Nongovernmental Organizations*. The World Bank Poverty & Social Policy Department. [on-line] Available:

http://www.wds.worldbank.org/servlet/WDSCContentServer/WDSP/IB/1996/05/01000009265_3961214180926/Rendered/IN.../multi0page.tx [date accessed: 12/07/02].

World Bank. (1998). *World Bank HIV/AIDS Interventions: Ex-ante and Ex-post Evaluation*. World Bank discussion paper number 389. [on-line] Available: <http://www.worldbank.org/aids-econ/interven.htm> [date accessed: 30/10/01].

World Bank (1999a) *Confronting AIDS: Public Priorities in a Global Epidemic*. Oxford, Oxford University Press.

World Bank. (1999b). *Project Appraisal Document on a Proposed Credit in the Amount of SDR 140.82 Million to India for a Second National HIV/AIDS Control Project*. Report number 18918-IN. Health, Nutrition and Population Sector Unit, SouthAsiaRegion. [http://www-](http://www-wds.worldbank.org/servlet/WDSCContentServer/WDSP/IB/1999/09/17/000094946_99060905302420/Rendered/I.../multi_page.tx)

[wds.worldbank.org/servlet/WDSCContentServer/WDSP/IB/1999/09/17/000094946_99060905302420/Rendered/I.../multi_page.tx](http://www-wds.worldbank.org/servlet/WDSCContentServer/WDSP/IB/1999/09/17/000094946_99060905302420/Rendered/I.../multi_page.tx) [date accessed: 05/07/02].

World Bank (2003) *Project Performance Assessment Report India National AIDS* http://www.wds.worldbank.org/servlet/WDSCContentServer/WDSP/IB/2003/08/30/000094946_03082104011041/Rendered/INDEX/multiOp [date accessed: 20/06/05].

World Bank. (undated). *Evaluation of the World Bank's HIV/AIDS Assistance*. The World Bank, Washington. Unpublished.

World Health Organization. (1988). *Guidelines for nursing management of people infected with human immunodeficiency virus (HIV)*. Geneva, World Health Organization.

World Health Organization. (1996). *The Global Programme on AIDS 1987-1995. The story of an international response to the pandemic. An executive summary*. Geneva. World Health Organization.

Xu, K., Evans, D.B., Kadama, P., Nabyonga, J., Ogwal, P.O., Nabukhonzo, P. & Aguilar, A. M. (2006). Understanding the impact of eliminating user fees: Utilization and catastrophic health expenditure in Uganda. *Social Science & Medicine* 62: 866-876.

Yates, S. (2004). *Doing Social Science Research*. London, Thousand Oaks, New Delhi, Sage Publications.

Yin, R.K. (1994). *Case Study Research. Design and Methods*. 2e Thousand Oaks, London, New Delhi, Sage Publications.

Zwi, A. (2000). Introduction. Policy Forum: The World Bank & International Health. *Social Science & Medicine* 50: 167-168.

Zwi, A. B. (1993) 'Reassessing priorities: identifying the determinants of HIV transmission'. *Social Science & Medicine*, 36 (5): iii-viii.

Zwi, A.B. & Cabral, A.J.R. (1991). Identifying "High Risk Situations" for Preventing AIDS. *British Medical Journal* 303: 1527-9.